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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Tuesday 14 November 1995

# Journal des débats (Hansard)

Mardi 14 novembre 1995

**Standing committee on  
administration of justice**

Organization

**Comité permanent de  
l'administration de la justice**

Organisation



Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
Greffière : Donna Bryce



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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Tuesday 14 November 1995

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Mardi 14 novembre 1995

*The committee met at 1534 in room 228.*

## ELECTION OF CHAIR

**Clerk of the Committee (Ms Donna Bryce):** Honourable members, it is my duty to call upon you to elect a Chair. Are there any nominations?

**Mr Tim Hudak (Niagara South):** I would like to nominate Gerry Martiniuk, the member for Cambridge.

**Mr Ed Doyle (Wentworth East):** I'll second that.

**Clerk of the Committee:** Are there any further nominations? There being no further nominations, I declare the nominations closed and Mr Martiniuk be elected Chair. Mr Martiniuk, if you would come and sit up at the front, please.

## ELECTION OF VICE-CHAIR

**The Chair (Mr Gerry Martiniuk):** Ladies and gentlemen, it's my duty to call upon you to elect a Vice-Chair. Are there any nominations?

**Mr Frank Klees (York-Mackenzie):** I nominate Ron Johnson.

**The Chair:** Thank you, Mr Klees. Are there any further nominations? If not, I'll move that nominations be closed and that Mr Johnson be elected Vice-Chair.

What are we doing now? Oh, a motion. I understand that I will accept a motion to appoint a subcommittee on committee business. Mr Ramsay.

## APPOINTMENT OF SUBCOMMITTEE

**Mr David Ramsay (Timiskaming):** I move that a subcommittee on committee business be appointed to meet from time to time at the call of the Chair, or at the request of any member thereof, to consider and report to the committee on the business of the committee; that the presence of all members of the subcommittee is necessary to constitute a meeting; that the subcommittee be composed of the following members: Mr Martiniuk, Chair, Mr Tilson, Mr Chiarelli and Ms Boyd; and that any member may designate a substitute member on the subcommittee who is of the same recognized party.

**The Chair:** Is there any discussion on the motion? If not, I'll call the question. All those in favour of the motion? All those opposed? Carried.

The clerk will now give us a briefing on the organization meeting.

## BRIEFING

**Clerk of the Committee:** I won't go into a lot of detail today regarding the committee because many of the new members got a lot of material at the new members' seminar and many experienced members will have knowledge from past experience.

The justice committee is one of four standing committees considered to be a policy field committee. As such, its mandate is to consider matters relating to the administration of justice in Ontario. The jurisdiction of this committee is over matters related to the following ministries: Attorney General, Solicitor General and Correctional Services, and Consumer and Commercial Relations.

Examples of legislation that the committee has dealt with in the past include the Substitute Decisions Act, the Human Rights Code Amendment Act, the Liquor Control Amendment Act, the Retail Business Holidays Amendment Act and the Police Services Act.

Along with considering legislation, this committee has written reports on issues such as conflict of interest, alternative dispute resolution, victims of crime, the control of ammunition and community-based crime prevention initiatives.

I point out that committees do not always deal with issues that are specific to their mandate. The House could choose to refer a bill or a matter to any committee for a number of reasons. You can't always predict which committees will consider which issues. For example, last year this committee spent a large amount of time dealing with the municipal planning reform act and the Employment Equity Act.

The scope of this committee's deliberations is defined by three areas:

The first is an order of the House referring a matter to the committee. This is usually a bill, either government or private member's, or a subject inquiry. The function of a committee on a bill is to go through the text clause by clause with a view to making amendments to render it more acceptable. A committee is, however, bound by the decision of the House given on second reading in favour of the principle of the bill and must not amend the bill in a manner destructive of that principle.

Committees will often hold public hearings on bills. This allows individuals or groups who have an interest in the bill to state their opinions and suggest changes to the bill. The consultations occur before the bill is reviewed clause by clause so that the committee can take these views into consideration.

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The process for considering any other matter that may be referred by the House is essentially the same as a bill except that instead of doing clause-by-clause, the committee may write a substantive report with recommendations.

The second area is standing order 108. This empowers the committee to study and report on all matters relating



to the mandate, management, organization or operation of the ministries outlined above, as well as the agencies, boards and commissions reporting to such ministries and offices. As long as the subject matter relates to a ministry assigned to the committee, the details and the duration of study are left to the committee to decide. This standing order is usually used when the committee agrees on what it wishes to study. The results of a study under the standing order may result in the writing of a substantive report with recommendations.

Standing order 125 is the third area, and it provides that in any calendar year, each member, other than the Chair, of the subcommittee on committee business is entitled to designate a matter other than a bill that may have been referred. There are two restrictions: (1) that the matter must relate to the ministry assigned to the committee; and (2) that the matter may only be considered up to a maximum of 12 hours of committee time.

I'll discuss 125s in more detail with the subcommittee, as those are the members who are entitled to move these designations. There is an exception to the way in which the subcommittee operates with 125s. The reports are deemed to be adopted. Under any other circumstance, the subcommittee must report its decisions to the committee and its report is amendable before voted on.

In terms of attaching priority to the order in which the committee will consider items, the standing orders clearly provide that government legislation and items designated under standing order 125 take priority, and in that order.

Sitting to the right of the Chair is Andrew McNaught, the research officer assigned to this committee. Andrew will provide a number of services for the committee, including drafting interim and final reports, preparing summaries of recommendations made in submissions to the committee, and providing briefings on certain issues as required.

If there are any questions now on either the mandate of the committee or the services provided by Andrew, we can take them now. No? Okay.

#### COMMITTEE BUSINESS

**The Chair:** Our next meeting will be on Monday, November 20. The subcommittee that you have elected today will be meeting either today right after the meeting, if they so choose, or we will meet tomorrow and report back to you next Monday. The only matter the subcommittee has before it at this moment is private member's Bill 11, An Act to amend the Expropriations Act and the Human Rights Code with respect to property rights.

If there are no other matters that anyone would like to raise at this time—

*Interjection.*

**The Chair:** I have received a copy of a motion that Mr Chiarelli may be moving before this committee today.

**Mr Robert Chiarelli (Ottawa West):** Yes, I will be. Is it appropriate for me to make that motion at the present time?

**The Chair:** I would imagine it should be considered by the subcommittee.

**Mr Chiarelli:** I would like the motion to be put and dealt with so that the subcommittee would have some-

thing live to deal with. If this committee approves the motion, then the subcommittee could deal with the details. In that case, I will move the motion, and I will read the motion as circulated by the clerk:

"Whereas the operation of the Ontario legal aid plan and the relationship of the Law Society of Upper Canada and the government of Ontario in relation to the plan have caused"—

**Mr David Tilson (Dufferin-Peel):** On a point of order, Mr Chair.

**Mr Chiarelli:** —“(1) a crisis in the public confidence in the reliability and effectiveness of legal aid in Ontario”—

**The Chair:** We have a point of order. Yes, Mr Tilson?

**Mr Tilson:** My understanding is that notice would first be given before a motion such as this be made and that it might be appropriate to serve notice on the committee that the motion is going to be made, and that the motion would then be voted on at a later date, presumably at the next meeting. To simply come and—on any committee that I've attended, on a motion such as this, of this magnitude, normally a notice of motion is made. With respect to Mr Chiarelli, I believe it would be more appropriate to serve notice on the committee that he intends to bring such a motion.

**The Chair:** I understand that the situation is that notice is not required for a motion of this kind. However, the committee can agree to have the matter deferred to some future time for consideration. It does not have to deal with it today.

**Mr Chiarelli:** I will read the motion, Chair.

"Whereas the operation of the Ontario legal aid plan and the relationship of the Law Society of Upper Canada and the government of Ontario in relation to the plan have caused:

“(1) a crisis in the public confidence in the reliability and effectiveness of legal aid in Ontario;

“(2) an Ontario judge to stay criminal proceedings against accused drug traffickers because of uncertainty of the legal aid plan;

“(3) ‘job action’ in the courts by Ontario lawyers to take place with additional job actions threatened;

“(4) both the Law Society of Upper Canada and representative groups of Ontario lawyers to launch separate court challenges to government action and inaction regarding legal aid;

“It is therefore resolved that the standing committee on administration of justice schedule public hearings forthwith into the status and operations of legal aid services in the province of Ontario and to report to the Legislative Assembly on or before December 14, 1995, with recommendations to quell the legal aid crisis and improve the delivery of legal aid services in a manner which will maintain the ‘judicare model’ of legal aid within a cooperative and workable financial and economic framework.”

That's the motion, Mr Chairman. If I may make brief comments with respect to it, I will say that as justice critic, critic for the Ministry of the Attorney General for



the official opposition, I received very significant representations from people interested in the administration of justice in the province, not the least of which is various groups of lawyers representing family law practitioners, criminal lawyers, legal aid clinics that are very concerned about the possibility of additional caseloads on the clinics without the resources to handle them, clinics which are already overburdened.

I believe it is in the public interest to have a forum for the public, and in particular these groups that are very, very concerned about the turmoil in the system at the present time, to be able to offer their advice, to be able to indicate what's happening on the ground with respect to legal aid.

I can only point out the recent circumstances where indeed we have judges in the Ontario courts who are now staying criminal procedure because of the uncertainty and the turmoil within the legal aid system, and I can only bring to everyone's attention the recent history of judges staying criminal procedures because of the court backlog because of the Askov case of not too long ago, and the sense of crisis that put in the system, indeed the number of criminal charges that in effect were stayed or permanently dismissed.

We see the seeds of this happening at the present time in criminal cases, and particularly when all parties and all governments are concerned about safety in the streets, we now have criminal trials being stayed because of government action or inaction, as it was indeed with the Askov case. That is completely unacceptable.

The other thing which is totally unacceptable in my mind, as a lawyer, as a member of the Law Society of Upper Canada at the present time, someone who practised for 18 years before I was elected to the provincial Legislature: There has been a traditional relationship of cooperation and understanding between the legal profession and the office of the Attorney General, and it would appear that at the present time that traditional partnership, that cooperation which has existed traditionally in Ontario, seems to be falling apart.

I think that we, as members of the provincial Legislature, have some obligation to try to quell the uncertainty, to try to calm the situation. I believe we need a forum for these lawyers, for the affected public to be able to come and express their point of view.

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I know that there's a sense of disenfranchisement among a lot of lawyers in the province, a lot of organized associations of lawyers, and I really do think that we have to try to provide that forum so that these people can express their opinions and give their advice to us as legislators, and that indeed we as legislators and MPPs would have some role to play in it.

That is the reason that I'm moving this particular motion. I believe that there is some public good to be served by having this committee have those public hearings, have the appropriate people invited to come before us. Indeed, we could therefore have some deliberations and make some recommendations to the Legislature on this very important issue.

**Mr Tilson:** This is an extensive motion, and of course I quite frankly have just had a short time to peruse it. As the member knows, there are a number of things going on with respect to legal aid at the present time. Mr Stanley Beck, as you know, is making an investigation with respect to the whole process of legal aid. There's some litigation going on; the law society has chosen to bring action against the government of Ontario. There are a number of complicated things with respect to this issue.

The Attorney General has made it quite clear to the legal profession and the people of Ontario that he will honour the memorandum of understanding that was entered into some time ago. That's not to say that there aren't problems with the legal aid plan. The fact of the matter is that it's got an overdraft of at least \$60 million, and the law society at convocation has, through proposed cuts, agreed to cut only something like \$7 million of that.

These are very complicated issues. There's litigation that's going on. I'm not so sure that this would be the appropriate time for this committee to deal with this motion, specifically with the litigation that's going on. I accordingly would move that this motion be deferred.

**Mr Chiarelli:** When I moved this motion, I didn't particularly think that the government majority on this committee would agree. I did it out of a sense of obligation to those people who feel disenfranchised on this particular issue.

There are large numbers of people who want to give advice to this Legislature. This is the people's place, particularly in committees, where people can come and have their say. It's all well and good for the government to say that it's a complicated issue and there's litigation pending and the Attorney General has agreed to honour a memorandum of understanding.

I'm prepared to go back to all these people, and there are many, and say, "I moved the motion and this government does not want to have you come here to speak to us in a formal setting," where their opinion will be recorded in public for everybody to see and hear, and for these individuals to see how we as elected representatives respond to them.

I can accept a majority decision not to have these public hearings, but I want on record that this government has said no to them, and I will tell them that this government has said no to them.

**Mr Tilson:** Mr Chairman, he's responding to comments that I made, and I didn't say that. I did not say that this government wasn't prepared to deal with this motion. You know perfectly well what you're trying to do. Don't hang the number on us that we're not prepared to listen and try to assist in a problem. There's a problem with respect to the providing of legal aid services in this province. Everyone in this room knows that. But don't come into this committee and start saying that we're not prepared to listen and try to deal with this issue.

The Attorney General has stood up in the House, has answered questions on this issue. He has made presentations to the Law Society of Upper Canada. He has done everything in his power at this particular stage to deal with this issue, and he is continuing to deal with this



issue. But don't come here and try to tell us that this government isn't responsive to this issue.

**Mr Klees:** If I might, with respect to the mover of this motion, I take great exception to using this committee forum for political grandstanding, because I believe the member knows that's exactly what he's been doing. I'm hopeful that this isn't an indication of how business is intended to be conducted here.

This is our first meeting. I don't know. I see at the header of this that it was faxed at 2:05 this afternoon, to somewhere from somewhere. Surely the member had given much more thought to the structuring of this motion, unless it was quickly cobbled together some time today. The member knew this committee would be meeting today. I would at least have expected that we would have received notification that this motion would be tabled today, would be moved today.

I think out of respect for the process, if in fact the member has serious concerns that this is the people's place, then I think we should also honour it as that. I truly hope this is not indicative of what we're in for over the next number of months.

I would certainly concur that this be deferred to give us an opportunity to, first of all, consider it seriously, if the member wants us to consider it seriously.

In light of the initiative that this government has already taken, I see absolutely no reason why the member feels he should go back to his public, as he is referring to them, to say that this government is not willing to listen. We are, but not on the basis of political grandstanding, which is what this is.

**Mr Gary L. Leadston (Kitchener-Wilmot):** I too would echo the same comments. You used two words in your remarks, "cooperation" and "understanding," and obviously that is not applying in your remarks or in your intent. I think the spirit of what you're saying—and we're all representatives of the people, but I think there's no supporting documentation. You mention the numbers that you have dialogued with. I'm not privy to that information as a representative of this committee.

I too would support the deferral until such time as I personally have that supporting documentation.

I would hope that this isn't indicative of the framework and the spirit of this committee. If we truly are representing the people of Ontario, I think we have to work in that same spirit, as you say, of cooperation and understanding, and I hope this is not the tone that this particular committee's going to take in the ensuing months.

**The Chair:** We are presently considering the motion to defer, I take it.

**Mr Ramsay:** There was no such motion.

**Mr Howard Hampton (Rainy River):** I wonder, Mr Chair, how can you have a motion to defer? It seems to me a motion was presented, and how then can you move on to a motion to defer?

As I read the motion, it's pretty clear. It says, "It is therefore resolved that the standing committee on the administration of justice schedule public hearings forthwith."

I just ask the clerk, how can we get then to a motion to defer? It seems to me a motion's been put. I don't know how you consider a motion to defer, even get a motion to defer on the table at this point in time.

**Mr Leadston:** Mr Chair, on a point of clarification: The motion to defer, in this forum, is it debatable?

**The Chair:** I'm advised by the clerk we're still dealing with the main motion.

**Mr Tilson:** Mr Chairman, I made a motion.

**The Chair:** Yes, I thought you did too.

**Mr Leadston:** There was a motion to defer.

**Mr Tilson:** As far as I'm concerned, notwithstanding what Mr Hampton's saying, I made a motion. It's on the floor and I expect it to be voted on. We've had debate going around the table before someone comes up with a bright idea that you can't make a motion to defer. I've never heard of such a thing. Of course you can make a motion to defer.

**Mr Hampton:** I guess we need a ruling from the Chair. Are you saying that a motion can be presented and then a motion to defer can be brought without consideration of the main motion? I just want to know what our procedural rules are going to be or what they have been.

**The Chair:** I see nothing improper with a motion to defer or table, whichever terminology the mover wants to make, and that's what I thought we were speaking to. The ruling will be then that there is a motion to defer on the floor which is to be spoken to along with the main motion. We will deal with Mr Tilson's motion first, before the main motion.

**Mr Leadston:** Mr Chairman, may I seek clarification?

**Mr Chiarelli:** That the motion is debatable. The motion to defer is debatable.

**Mr Leadston:** Mr Chairman, it is my understanding that a motion to defer is non-debatable. I believe it was a motion to defer; it was not to table. That's the difference. It's taken in a different context. If the clerk could advise us, am I correct that a motion to defer is non-debatable and that motion takes precedence over the motion as presented by the honourable member?

**Clerk of the Committee:** A motion to defer is normally not debatable; a motion to defer, with reasons, is debatable. I wasn't clear on what exactly Mr Tilson's motion—were you giving a time frame to defer it?

**Mr Tilson:** No.

**Clerk of the Committee:** Just defer indefinitely?

**Mr Tilson:** Yes.

**Clerk of the Committee:** In that case then, it would be in order to go to that vote.

**Mr Chiarelli:** Can we have a recorded vote, please?

**The Chair:** We are now dealing with Mr Tilson's motion to defer. We will put the question.

**Mr Doyle:** I'll second that motion.

**The Chair:** We do not need a seconder. We're going to deal with Mr Tilson's motion to defer the main motion.

All those in favour of the motion to defer, raise your hands. A recorded vote has been requested.



**Ayes**

Doyle, Guzzo, Hudak, Johnson, Klees, Leadston, Parker, Tilson.

**The Chair:** All those opposed.

**Nays**

Boyd, Chiarelli, Conway, Hampton, Ramsay.

**The Chair:** The motion to defer carries.

**Mr Chiarelli:** I'm truly shocked that you guys wouldn't let us debate this motion.

**The Chair:** You did.

There being no other business before this committee, we are adjourning to November 20, and the subcommittee, if it wishes, could meet immediately afterwards.

*The committee adjourned at 1604.*

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## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

- \***Chair / Président:** Martiniuk, Gerry (Cambridge PC)
- \***Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)
- \*Boyd, Marion (London Centre / -Centre ND)
- \*Chiarelli, Robert (Ottawa West / -Ouest L)
- \*Conway, Sean G. (Renfrew North / -Nord L)
- \*Doyle, Ed (Wentworth East / -Est PC)
- \*Guzzo, Garry J. (Ottawa-Rideau PC)
- \*Hampton, Howard (Rainy River ND)
- \*Hudak, Tim (Niagara South / -Sud PC)
- \*Klees, Frank (York-Mackenzie PC)
- \*Leadston, Gary L. (Kitchener-Wilmot PC)
- \*Parker, John L. (York East / -Est PC)
- \*Ramsay, David (Timiskaming L)
- \*Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service



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First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

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Lundi 20 novembre 1995

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**Comité permanent de  
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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Monday 20 November 1995

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Lundi 20 novembre 1995

*The committee met at 1536 in committee room 2.*

## SUBCOMMITTEE REPORT

**The Chair (Mr Gerry Martiniuk):** I see a quorum. Can we proceed? I firstly call this meeting to order. I'll read the report of the subcommittee into the record.

"Your subcommittee met on November 14, 1995, and recommends that consideration of Bill 11, An Act to amend the Expropriations Act and the Human Rights Code with respect to property rights, be postponed."

I would ask for a mover to adopt the report.

**Mrs Marion Boyd (London Centre):** So moved.

**The Chair:** Any discussion or amendments?

**Mr David Ramsay (Timiskaming):** Just a question. Does the subcommittee have any recommendation of when we may be considering this bill?

**The Chair:** No.

**Mr Frank Klees (York-Mackenzie):** For clarification, being new to the process, what exactly does the word "postponed" mean? Does that mean this bill can be brought forward for consideration at any time?

**The Chair:** The word is the same as "deferred." It could be brought back by a committee member at any time, but it's an indefinite postponement.

**Mr Klees:** I just want to register that I consider the issue of property rights to be one of the utmost importance. I wasn't privy to the discussions of the subcommittee as to the reason for the postponement, but I'd like it to be understood that I for one would like to see us deal with this issue at some point.

**The Chair:** Is there any further discussion in regard to the motion to adopt the subcommittee's report?

**Mr John L. Parker (York East):** I would just make the point that I would not expect our workload to be less in future than it is now and I'm assuming that the subcommittee has looked into that and satisfied itself that there will be time some time in the future to deal with this. I imagine it's being deferred because there are other matters that we should be getting on with. On that understanding, I have no problem with what's being suggested, but I just look to you for some assurance that that's in fact something we can count on.

**The Chair:** As it is being postponed, it still means it's on our agenda and can be revived at any time by the committee if they see fit.

Is there any further discussion? If not, I'll put the question. All those in favour of the motion? Carried.

I understand Mr Ramsay might wish to make a motion.

**Mr Ramsay:** I move that Mr Ramsay replace Mr

Chiarelli as the permanent member of the subcommittee on committee business.

**Mr David Tilson (Dufferin-Peel):** On a point of order, Mr Chair: Isn't that normally done in the House? I'm not objecting to it. I'm just asking a question on procedure. My understanding is that the House votes as to who sits on this committee.

**Mr Ramsay:** No, I said the subcommittee. I'm just replacing our representative on the subcommittee.

**Mr Tilson:** Oh, the subcommittee. Sorry. Sure.

**The Chair:** Are there any questions or any discussion in regard to the permanent substitution, I take it, of Mr Ramsay on the subcommittee? If not, all those in favour of the motion? Carried.

For the information of the committee, we do have a filing under standing order 125 made by Mr David Ramsay as he is now a member of the subcommittee. I understand that filing is in order and I would suggest that filing will be dealt with by the subcommittee at the appropriate moment. Do we need a motion? No. That's for your information.

Are there any other matters that any member of the committee would like to raise at this time?

**Mr Parker:** Could you let us in on what the section 125 motion is, or is that not in order?

**The Chair:** You mean the motion itself? If you wish. I thought the subcommittee would deal with it and then bring it before us.

**Mr Parker:** It would be kind of fun to know what it's about. That's all.

**The Chair:** I'll read it into the record. It's dated November 16, from Mr Ramsay, directed to the clerk of this committee, and it reads:

"For the purpose of standing order 125, I would like to request that the standing committee on the administration of justice meet for 12 hours to deliberate the impact of the halfway house closures and the proposal to replace this form of monitoring inmate reintegration into the community with the introduction of electronic monitoring, with particular attention paid to the experiences of other jurisdictions that have taken similar actions."

I would suggest that since there are no matters before this committee, we now adjourn at the call of the Chair, if that is suitable. Could I have a motion to that effect?

**Mrs Boyd:** So moved.

**The Chair:** Thank you very much. That concludes our business here today.

*The committee adjourned at 1542.*

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- Chiarelli, Robert (Ottawa West / -Ouest L)
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- \*Leadston, Gary L. (Kitchener-Wilmot PC)
- \*Parker, John L. (York East / -Est PC)
- \*Ramsay, David (Timiskaming L)
- \*Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

**Substitutions present / Membres remplaçants présents:**

Skarica, Toni (Wentworth North) for Mr Guzzo

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** Stobo, Carolyn, research officer, Legislative Research Service



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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Monday 11 December 1995

# Journal des débats (Hansard)

Lundi 11 décembre 1995

**Standing committee on  
administration of justice**

**Comité permanent de  
l'administration de la justice**

Subcommittee report

Rapport du sous-comité

Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
Greffière : Donna Bryce



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## LEGISLATIVE ASSEMBLY OF ONTARIO

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICECOMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Monday 11 December 1995

Lundi 11 décembre 1995

*The committee met at 1536 in room 228.*

## SUBCOMMITTEE REPORT

**The Chair (Mr Gerry Martiniuk):** The first order of business is the report of the subcommittee for the standing committee on administration of justice. You should all have a copy of that report, and for the purpose of Hansard I will read it into the record:

"Your subcommittee met on December 4, 1995, with respect to the consideration of Bill 19, Advocacy, Consent and Substitute Decisions Statute Law Amendment Act, 1995, and recommended the following:

"1. The Chair will request the House leaders to authorize the committee to sit for four weeks during the recess; public hearings to start on January 15, 1996.

"2. The committee will meet for four weeks divided as follows: one week of public hearings in Thunder Bay, Ottawa, London and Windsor; two weeks of public hearings in Toronto and one week of clause-by-clause consideration of the bill in Toronto.

"3. Staff from the ministries of Attorney General, Health and Citizenship, Culture and Recreation will be requested to provide a briefing to the committee for three hours on the first day of public hearings in Toronto.

"4. The Minister of Health will be invited to make a statement to the committee. The opposition critics will also have the opportunity to make a statement.

"5. The committee will advertise in newspapers in the areas in which public hearings are to be held, as identified by the subcommittee.

"6. The time slots for witnesses will be 30 minutes. However, should there be more witnesses than can be accommodated in Thunder Bay, Ottawa, London and Windsor, the time slots will be 20 minutes.

"7. The clerk is authorized to arrange the scheduling of witnesses and the daily itinerary of the committee as discussed by the subcommittee.

"For the purpose of Bill 19 and any other matter that may be referred to the committee over the winter recess, the Chair and the clerk, in consultation with the subcommittee, shall have the authority to make all arrangements necessary for the orderly consideration of such matters."

Could I have a mover for the report? Mr Leadston? It has been moved. Is there any discussion?

**Mr Rosario Marchese (Fort York):** On the issue of the time that we might allow the Ministry of Health to brief the committee, my experience is that three hours is a long time. I'm not quite sure what some of the Liberal members might have said. I'm not sure whether they

proposed that as well. But I would think an hour would be more than sufficient for that purpose and that we should leave the additional time for deputations, as opposed to giving the Minister of Health three hours to do that. I'm not sure whether there's support for this, but I would move that instead of three hours we allow for one hour of debriefing from the ministry. I would move that as a friendly amendment.

**Mr Ed Doyle (Wentworth East):** That's not the way I understood it.

**Mr Marchese:** If the three hours is not there, then what do we mean?

**Mr Doyle:** It says, "Staff from the ministries of Attorney General, Health and Citizenship, Culture and Recreation will be requested to provide a briefing to the committee for three hours." It's more than one group, as I read it anyway. There are a number of groups there for a three-hour period, as I understand it. Am I misunderstanding it?

**Clerk of the Committee (Ms Donna Bryce):** That's correct.

**The Chair:** It's more than one ministry. It's three ministries.

**Mr Marchese:** I understand. I still think if the three ministries come together and they're doing a presentation together, the one hour is sufficient. Is it your sense, Mr Ramsay, that you need more time or that we would need more time?

**Mr David Ramsay (Timiskaming):** No.

**Mr Marchese:** If that's the case, then I move that we provide one hour to hear from the various ministers.

**The Chair:** The subcommittee report, by the way, is a meeting, just so you're aware, of Mr Ramsay, Mrs Boyd and Mr Tilson and that was their recommendation. But we have a motion to amend the subcommittee report to the committee, in particular item 3. The amendment is to delete the requirement of three hours?

**Mr Marchese:** Yes, and allow for one hour from the various ministries.

**Mr Ramsay:** May I just get a point of clarification? When you asked me, did we need more time, didn't you ask me more time than the three hours?

**Mr Marchese:** No. Sorry. I was proposing one hour, and did you feel that somehow we needed all three hours?

**Mr Ramsay:** Oh. That's different. We did agree in subcommittee on the three hours. We had quite a bit of debate on that. I guess we're talking four weeks alto-

gether of hearings, so we said three hours since there are three bills and different ministries.

**Mr Gary L. Leadston (Kitchener-Wilmot):** I'm not in disagreement with what is being proposed, but why not give us the flexibility and the leeway and provide a briefing to the committee for up to three hours? If we're 40 minutes or we're an hour and 10 minutes, if we go an hour and 10, they may be the most salient points in the last 10 minutes but the motion says, "one hour." So why not "up to three hours"?

**Mr Doyle:** They can take 20 minutes.

**Mr Leadston:** They can take 20 minutes.

**Mr Marchese:** I appreciate the point, and under normal circumstances that would be all right. But my experience is if you give people the "Up to," it means that ministries organize themselves for three hours essentially. They might not, but I think we could probably get the essential information we need from the ministries in that one hour. If you stretch it, you just allow them to say a lot more than what I think we need.

**Mr Leadston:** Can we clarify with the ministries and say that we will allot them 20 minutes each? That's a total of 60 minutes.

**Mr David Tilson (Dufferin-Peel):** Mr Marchese, this matter was debated for a considerable period of time in subcommittee. Minister Wilson has expressed an interest to come and speak to the committee. I doubt if Minister Mushinski or Minister Harnick will, but Minister Wilson has indicated an interest.

Normally, with any of the committees you and I have attended on, the ministers come and address the committees and there's an opportunity for members of the committee, if they wish, to ask questions of the ministers. As well, normally on committees that you and I have sat on, staff from a particular ministry—in this particular case there happen to be three ministries—have been given an opportunity to explain the rationale for the proposed changes.

As you know, there are some substantial changes, many of which you indicated when you were speaking in the House, particularly to the Advocacy Commission, and areas that you personally have expressed an interest in as a member in the House. Originally when I as a member of the government was requesting time, the request was for substantially more than three hours, and it was on the usual good persuasion of Mr Ramsay and Ms Boyd that I agreed to lower that time to three hours, as a member of the subcommittee representing the government.

I can tell you that you're changing tradition in this place when you suggest one hour. Most committee members want to be informed what the particular ministry—or in this case ministries—is doing, and I think it's mandatory that not only the committee members but members of the public have an opportunity to hear from those faceless bureaucrats in the background as to their explanation and rationale for the changes.

**Mr Ron Johnson (Brantford):** I was going to actually speak somewhat in the same tone as Mr Tilson with respect to Mr Marchese. I think a lot of it too is I know as a member I want to be able to, when listening to

delegations and at the same time in terms of my questioning, have a very detailed background briefing from ministry staff, and I'm not convinced that we can get that in one hour.

I think a lot of it is really incumbent upon us as members to learn a lot of this stuff as well, but to be able to ask questions of ministry staff is very important. I don't know that I'm completely comfortable with the one-hour time frame. I think three hours is the minimum I would require as a member to make the kind of informed decisions that I want to make.

**The Chair:** We're going to call the vote on the amendment—I'm sorry, I don't want to cut you off.

**Mr Marchese:** No. I think we've had enough on this.

**The Chair:** We're voting on the amendment to alter and amend the subcommittee report to reduce the amount of time to be heard from possibly three ministers from three hours to one hour.

All those in favour of the amendment? Recorded: Mr Marchese.

All those against the amendment? The amendment fails.

We are now dealing with the subcommittee report, and we have a motion on the floor by Mr Leadston.

**Mr Leadston:** I'm not sure whether it was a grammatical error, but you referred to an item 6 reading, "However, should there be more witnesses than"—on my copy it says "may" and you said "shall." Does yours read "shall"?

**The Chair:** No, mine says "may." Did I say "shall"? Freudian slip. Sorry, Mr Leadston.

Is there any further discussion with regard to the subcommittee report?

All those in favour of the report? Carried.

**Mr Ramsay:** Do we have any more updates with regard to timing of the sitting of this committee?

**The Chair:** No, we do not. The question was directed. The House leaders had requested that we sit in the month of February, but because of extenuating circumstances, we have requested to start on January 15 rather than February 2 or 3. We do not know that yet, and we will let you know. That's all we can do at this moment.

**Mr Ron Johnson:** Being new to the process I'm not sure exactly how this works—it does indicate one week of public hearings in Thunder Bay, Ottawa, London and Windsor. Now is that the first week of public hearings that we do the travel? Is that decided?

**The Chair:** The subcommittee will decide that.

**Mr Ron Johnson:** Oh, that hasn't been decided yet. Okay.

**Mr Marchese:** Do you have a suggestion?

**Mr Ron Johnson:** Quite frankly, it doesn't make a big deal of difference. Just for scheduling purposes.

**The Chair:** If there's no other business, we will adjourn this meeting at the call of the Chair.

*The committee adjourned at 1550.*











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*\*In attendance / présents*

**Substitutions present / Membres remplaçants présents:**

Marchese, Rosario (Fort York) for Mrs Boyd

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service



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First Session, 36th Parliament

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Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Monday 5 February 1996

# Journal des débats (Hansard)

Lundi 5 février 1996

## Standing committee on administration of justice

## Comité permanent de l'administration de la justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui



Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
Greffière : Donna Bryce

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LEGISLATIVE ASSEMBLY OF ONTARIO  
**STANDING COMMITTEE ON  
 ADMINISTRATION OF JUSTICE**

Monday 5 February 1996

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO  
**COMITÉ PERMANENT DE  
 L'ADMINISTRATION DE LA JUSTICE**

Lundi 5 février 1996

*The committee met at 1303 in room 151.*

ADVOCACY, CONSENT  
 AND SUBSTITUTE DECISIONS  
 STATUTE LAW AMENDMENT ACT, 1995  
 LOI DE 1995 MODIFIANT DES LOIS  
 EN CE QUI CONCERNE L'INTERVENTION,  
 LE CONSENTEMENT ET LA PRISE  
 DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

**The Chair (Mr Gerry Martiniuk):** I see a quorum. This is the standing committee on administration of justice and the consideration of Bill 19, for the month of February.

I welcome the substitute members that we have present. Helen Johns, the member for Huron, is the parliamentary assistant to the Minister of Health. Tony Clement, Brampton South, is the parliamentary assistant to the Minister of Citizenship, Culture and Recreation. Elinor Caplan, former Minister of Health and member for Oriole, is the opposition Health critic. Bernard Grandmaître is a former Minister of Municipal Affairs and the member for Ottawa East. Rosario Marchese is a former Minister of Culture and Communications.

Other members: Ron Johnson, Vice-Chair of this committee; Garry Guzzo, member for Ottawa-Rideau; David Tilson, parliamentary assistant to the Attorney General and the member for Dufferin-Peel; Marion Boyd, former Attorney General of Ontario and the member for London Centre and now the third party's Justice critic; Gary Leadston, member for Kitchener-Wilmot; David Ramsay, former Solicitor General of Ontario and the member for Timiskaming; Ed Doyle, the member for Wentworth East; John Parker, the member for York East. I think that covers everyone.

ATTORNEY GENERAL  
 MINISTER OF CITIZENSHIP,  
 CULTURE AND RECREATION  
 MINISTER OF HEALTH

**The Chair:** Today we have on our agenda three ministers: the Honourable James Wilson, Minister of Health;

the Honourable Charles Harnick, the Attorney General of Ontario; and the Honourable Marilyn Mushinski, Minister of Citizenship, Culture and Recreation.

It's suggested to the committee, unless there is an objection, that we would hear presentations from all three ministers and then there would be the opportunity for the statements from the opposition and questions to all three ministers. If that is acceptable, we'll proceed in that manner. The Honourable Charles Harnick, I understand that you will make your presentation first.

**Mrs Elinor Caplan (Oriole):** Are copies of the minister's statement going to be tabled with the committee?

**The Chair:** Is there a written statement to be filed with the committee, Mr Harnick?

**Hon Charles Harnick (Attorney General, minister responsible for native affairs):** No.

**The Chair:** I believe the answer is no, Mrs Caplan.

**Hon Mr Harnick:** Today, in keeping with the government's promise to the people of Ontario, we are embarking on an important stage in implementing the changes proposed in Bill 19, the Advocacy, Consent and Substitute Decisions Statute Law Amendment Act. Over the next four weeks, you will have an opportunity to hear from members of the public across the province and to provide feedback yourselves on the new law.

This important new law will reduce government interference in the private affairs of individuals. It will also place decision-making where it belongs—in the hands of individuals and their families. Important features of Bill 19 include repealing the Advocacy Act and abolishing the Advocacy Commission, which interferes in the private lives of vulnerable people and the people who care for them; replacing the Consent to Treatment Act, an unnecessary, bureaucratic and intrusive law, with the Health Care Consent Act, reducing delays in treatment for mentally incapable people; and amending the Substitute Decisions Act to ensure that powers of attorney are protected, to reduce barriers to family members who apply to become statutory guardians, to expand the categories of family members who can apply to be a statutory guardian to include in-laws and extended family, to simplify the rules for making and using powers of attorney, and to ensure that decision-making is in the hands of individuals and their families.

During the past year and a half, many Ontarians have expressed serious concerns that the existing laws are too complicated and bureaucratic and give the government too much power to intervene in the lives of ordinary people. Many of you have previously acknowledged the uneasiness expressed by your constituents over these laws. These amendments respond directly to criticisms heard over and over again across Ontario.

My colleagues the Minister of Health and the Minister of Citizenship, Culture and Recreation will be talking in greater detail about their aspects of the bill. I would like to speak now about the amendments to the Substitute Decisions Act that will be affected by Bill 19. Before I discuss some of the major areas of change, I think it would be useful to describe our fundamental objectives.

These amendments will retain the basic principles of the act—respect for personal choice and enhancement of the dignity of mentally incapable people. They will respond to the intense public concerns about potential government interference with powers of attorney. They will clarify that private arrangements people make to plan for possible future incapacity will have first priority. They will provide more opportunity and easier processes for family to become substitute decision-makers if advance planning has not occurred. They will streamline procedures, reducing bureaucratic red tape and complexity.

They reflect this government's belief that the majority of family members, service providers and caregivers are acting in good faith and with good intentions. They will eliminate the involvement of the expensive and intrusive professional advocate in the procedures for appointing guardians. The amendments will clarify that the public guardian and trustee will act as guardian only as a last resort, when there is a critical need and there is no other suitable person available or willing to act. The amendments will facilitate the involvement of local community volunteers in providing assistance with guardianship services.

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For these objectives to be meaningful, it is important to understand the law before the Substitute Decisions Act, the underlying purposes of the current Substitute Decisions Act and the reasons why this government has acted to amend the act while preserving its basic principles.

The current Substitute Decisions Act, as I have acknowledged in the past, is a well-intentioned attempt to address the need for a comprehensible and complete set of rules for decision-making for mentally incapable people. There is no doubt that there were serious gaps and defects in this area of the law before the previous government's reform. For example, prior to the current Substitute Decisions Act, individuals could only plan ahead for financial matters.

There has been increasing recognition of the importance of decisions which have a profound effect on health and quality of life. People have come to consider these types of decisions as important as financial decisions. One illustration of this has been the increasing interest in the concept of living wills and increasing demand that government make it clear that these choices will be respected. So in introducing the power of attorney for personal care and confirming the legality of living wills, the legislation was a significant improvement.

However, it also created unnecessarily complicated procedures for using this power of attorney for personal care if the need should arise. The procedures were expensive in that they involved obtaining two capacity assessments. They were also time-consuming in that they required the completion of a detailed guardianship plan

to be filed with the office of the public guardian and trustee and then waiting for an advocate to visit the incapable person to give him or her rights advice.

Even after the attorney goes through this process, a person who has already been assessed two times and found incapable is allowed to stop the power of attorney from being used. In reality, this makes a power of attorney for personal care of little use to most people. No one wants that result, least of all the many people who have taken the time over the last few years to make a power of attorney for personal care. That is why the government is amending the Substitute Decisions Act to make it easier for everyone to use powers of attorney for personal care.

Attorneys who wish to act for incapable people will no longer be required to go through elaborate procedures just to get formal acknowledgement of their authority to act on behalf of the incapable person. The power of attorney will speak for itself. The attorney will not be required to file anything with the public guardian and trustee or receive permission from that office before acting as a substitute decision-maker. This is just one example of many instances where Bill 19 is simplifying an improvement to the law that the Substitute Decisions Act makes excessively complicated.

As much as the changes in the area of personal care brought about by the Substitute Decisions Act were a big step forward in principle, this is not true in the area of financial planning. Although I have confidence that the government of the day had the best intentions, the actual results of the changes to financial powers of attorney seriously alarmed the public.

Before the Substitute Decisions Act, financial powers of attorney were paramount. People did not have to be concerned that their private arrangements could be interfered with by the government. The Substitute Decisions Act changed this and increased the possibility of government involvement in these situations. This is simply unacceptable to the public, as I am sure many of you have heard repeatedly from your constituents. Bill 19 will restore the integrity of private planning by introducing barriers to government involvement. It will do this without in any way jeopardizing the validity of powers of attorney which have already been made.

There was one change made to the law by the Substitute Decisions Act that caused considerable public concern. Prior to the Substitute Decisions Act, a continuing power of attorney for property was not terminated when the individual who made it was assessed and found incapable of managing property. The public guardian and trustee would not take over and manage the property of an incapable person who had previously made a continuing power of attorney. The Substitute Decisions Act altered this.

Under the current act, a person who has made a continuing power of attorney might later be formally assessed and found incapable. At this point, the public guardian and trustee is required to step in and take over management of the property. To get permission to manage the property, the attorney has to apply to the public guardian and trustee.



This was not an improvement. It was an unacceptable level of intervention in people's private affairs. In this instance, the law prior to the Substitute Decisions Act was better, and we are amending the act so that a continuing power of attorney will once again not be terminated when a person becomes mentally incapable.

It needs to be acknowledged that even with mechanisms in law to plan ahead, there are some people who do not or cannot take advantage of this opportunity. The existing Substitute Decisions Act improved on earlier laws relating to situations where incapable individuals have not planned ahead and made powers of attorney for property.

Prior to the Substitute Decisions Act, there were only two ways such persons could get a substitute decision-maker. First, the person might be assessed and found incapable under the Mental Health Act. However, this would happen only if the person had entered the province's mental health system, which would not normally happen in the case of someone who became incapable as the result of a stroke or a disease such as Alzheimer's. And in every case it would result in the public guardian and trustee becoming the statutory guardian of the incapable person's property. If someone else wanted to be an incapable person's guardian of property, he or she would have to use the second route and apply to court for permission. This was the rule even if the proposed guardian was the incapable person's spouse or child. This court application was usually expensive and time-consuming.

The current Substitute Decisions Act improved this situation by permitting a spouse or partner, child, parent or sibling to apply directly to the public guardian and trustee to replace it as the statutory guardian. With Bill 19, we are further expanding the opportunities for family members to be appointed as statutory guardians without being required to go to court. We are doing this by opening up the category of family members who can act as statutory guardians to include anyone related to an incapable person by blood, marriage or adoption. As I said at the time of second reading, we know that families do not begin and end with parents, children or siblings. It has been gratifying to hear positive comments from members such as the member for Oriole about the wisdom of this amendment.

Another amendment under Bill 19 that has made it easier for those applying to become statutory guardians is the removal of the mandatory requirement to post security. Under Bill 19 the public guardian now has the discretion to request security.

There is always an option to apply to court to be appointed guardian, and Bill 19 has made this process easier. Amendments to Bill 19 have made many of the procedures that do have to be brought before court cheaper and less time-consuming by allowing certain applications to be brought by way of motion, which is a less complicated, cheaper and quicker court procedure.

Before the Substitute Decisions Act, there were details in the law concerning the powers, duties and accountability of financial guardianship. In contrast, with respect to personal guardianship, none of these issues were addressed. The act now contains detailed provisions regarding both, which is an improvement.

Bill 19 further improves the situation by reducing the complexity of and simplifying these provisions while retaining the essential elements of being responsible for making decisions on behalf of another person. Now the powers, duties and restrictions on substitute decision-makers for personal care have been simplified and in some cases eliminated in order for substitute decision-makers to do their job. For example, substitutes will no longer be required to prepare annual reports; it will be sufficient to keep written records. Further, under Bill 19 there are now fewer limits on the decisions that can be made by substitutes, again making it easier to do what is in the best interests of the person.

Prior to the Substitute Decisions Act, there were only very limited provisions to ensure that people who were affected by guardianship procedures were informed of their legal rights. The act introduced a very rigid, formal and expensive scheme for providing this information that always required meeting with a government-funded advocate. With the elimination of the Advocacy Commission, we need to find better ways of making sure information about legal rights is available.

Under Bill 19, people who are affected by the Substitute Decisions Act will still be informed of the legal avenues that are available to them, but in a less bureaucratic, simpler way that can be made to suit the situation of the individual.

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Section 10 of Bill 19 proposes changes to section 16 of the Substitute Decisions Act which will require the public guardian and trustee to inform incapable people for whom it is appointed as guardian of their legal right to appeal to the Consent and Capacity Review Board. This will be a legal obligation, and compliance by the Office of the Public Guardian and Trustee will be mandatory.

In addition, section 46 of Bill 19 will require that every time a court application is made for guardianship, the person who is applying will have to inform the person who is alleged to be incapable of their rights or give the court an explanation as to why they could not do this. In this way, the judge will ensure that information that is appropriate in the circumstances has been provided.

We have considered the legal issues carefully and we are satisfied that these are appropriate and sufficient safeguards. The rights advice provisions of the Substitute Decisions Act will still, after Bill 19 is enacted, be the most rigorous that any province in Canada requires in similar circumstances.

Our goal throughout our review of the Substitute Decisions Act that led to the introduction of Bill 19 was to improve the act. As I acknowledged earlier, there were many laudable concepts introduced into the law by the Substitute Decisions Act, such as the power of attorney for personal care. Another of these was the recognition in the law of the validity of documents such as living wills. That is why we are not changing this part of the act. After it is amended by Bill 19, the Substitute Decisions Act will continue to provide that living wills and other similar documents are legally binding on an incapable person's substitute decision-maker.

At its core, the Substitute Decisions Act represented an attempt to create a scheme for substitute decision-making on behalf of incapable persons that would facilitate



advanced planning for incapacity, address the needs of incapable persons, and give families and government the appropriate means they would each need to assist and protect them. The complexity of the scheme in the current Substitute Decisions Act, as well as some overly intrusive provisions, simply frustrated the good intentions that underlie the act. I believe the amendments introduced by Bill 19 will result in a Substitute Decisions Act that will truly serve the needs of Ontarians.

In closing, I would also like to express my appreciation to the members of this committee for their anticipated hard work and dedication. I am confident that the next four weeks will be extremely productive, providing us with constructive feedback on important laws that affect every one of us. Thank you very much.

**The Chair:** Thank you, Mr Harnick. My apologies. I did not introduce an additional member of our committee, Mr Frank Klees—I didn't see you—who is the member for York-Mackenzie and also the parliamentary assistant to the Minister of Natural Resources.

We will now hear from Marilyn Mushinski, the Minister of Citizenship, Culture and Recreation.

**Hon Marilyn Mushinski (Minister of Citizenship, Culture and Recreation):** Thank you, Mr Chairman. First of all, let me tell you how pleased I am to appear before this committee today to address an issue of importance to the people of this province.

In Bill 19, which was introduced for first reading by my colleague the Attorney General on November 15, 1995, provision is made to repeal the Advocacy Act and eliminate the Advocacy Commission. This provision will restore common sense where it is most needed. It will allow us to focus on a more community-centred and, frankly, more sensible approach to the provision of advocacy for vulnerable adults.

I know that some of the individuals the Advocacy Act was meant to help are concerned about its repeal. They want to know why we are taking this step and what we intend to do to help protect the interests of vulnerable adults. I would like to address those questions today.

Advocacy is defined in most dictionaries as the act of speaking or pleading on another person's behalf. Families, volunteers, self-help groups, community agencies and members of the caring professions have been doing so for decades, and in most cases very effectively, but the former government believed that it could do better by establishing the Advocacy Commission, an \$18-million-a-year bureaucracy that would serve as protector of vulnerable people and oversee the provision of advocacy throughout Ontario.

Under the legislation, the commission could authorize community agencies to provide advocacy services on its behalf. There was an important proviso, however: Community agencies could only be authorized if their sole function was to provide advocacy services. This meant, for example, that an agency would not be authorized if it delivered Meals on Wheels to seniors, because doing so was perceived to be a conflict of interest. The net effect was that many community agencies that were providing necessary and important services to vulnerable adults but were also advocating on behalf of their clients could not be authorized to do advocacy on the commission's behalf or be eligible for commission funding.

Our position is different from that of the former government. We believe that the majority of families, friends, volunteers, community agencies and service providers are both willing and able to advocate effectively for vulnerable adults, and to do so in a way that respects their wishes.

Under the provisions of the act, commission-authorized advocates were given the power to enter virtually any place that vulnerable people lived or received care and treatment. This included institutions, hospitals, nursing homes, boarding-houses, sheltered workshops, day care facilities, schools, and yes, even private homes. If they weren't refused entry, they could go into such places without a warrant and at any reasonable hour. What was reasonable was largely left up to the commission. If advocates were refused entry, they could seek a warrant from a justice of the peace. If the warrant was granted, they could gain entry, if necessary with the assistance of the police. They also had the power to examine records belonging to facilities such as hospitals, in some cases without the consent of the vulnerable person to whom the records related. Commission advocates could use these powers even when they were not responding to an allegation of abuse and there was no evidence that a vulnerable person was in need of protection.

We believe, as do many members of the medical community, many family organizations and other critics of the Advocacy Act, that the powers given to commission advocates were excessive, that the intrusion of strangers into other people's affairs would inevitably create tension and conflict within families and between vulnerable people and members of the medical profession.

We will eliminate this adversarial approach by restoring and strengthening the role that families, volunteers and community-based agencies have always played in the lives of vulnerable adults. We intend to take a different approach to the provision of advocacy by promoting partnerships among the many dedicated individuals and organizations who are already advocating on behalf of vulnerable adults. We will work cooperatively with them to coordinate efforts to make the best use of collective resources and expertise, to develop effective mechanisms for addressing abuse and neglect, and to link vulnerable adults and their families to information, services and other forms of assistance.

In developing a new approach to protecting the interests of vulnerable adults, we are listening to the views of people reflecting the perspectives of community organizations, seniors, people with disabilities, volunteers, medical professionals, service providers and, most important, families. Our approach will reflect this government's commitment to protecting the interests of vulnerable people in a way that is sensitive, responsive and cost-effective.

**The Chair:** Thank you, Madam Minister. We'll now hear from the Honourable James Wilson, Minister of Health.

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**Hon Jim Wilson (Minister of Health):** Thank you, Mr Chair. I am pleased to address the committee today and add my strong support for Bill 19, which was tabled by my colleague the Attorney General for second reading last November.



An important part of Bill 19 is the Health Care Consent Act, which replaces the flawed Consent to Treatment Act.

As lawmakers, it is essential that we achieve maximum clarity in directing health care professionals, families and caregivers on how to ensure incapable individuals are treated fairly and compassionately when they are unable to consent to treatment on their own. In providing this direction, we are required to consider whose interests we are trying to protect and the intended social goal or purpose we aim to achieve. We have a responsibility, therefore, to bring forward clear, concise and thoughtful legislation. Confusing legislation leads to an obscuring of policy goals and in the end leaves those we sought to protect unprotected. This has become the fate of the Consent to Treatment Act.

What is required is a realistic and workable framework for health practitioners to obtain consent to treatment, a framework that also permits appropriate substitutes to step in to ensure a loved one receives necessary treatment when required. I believe we have created that framework in the new legislation. By revising the previous government's legislation, this government is responding directly to the very real, very troubling issues that have been raised by families, health care providers and caregivers over the last several years.

I speak to this bill today not only as Minister of Health but also as a member who has met with the concerned families, received the phone calls from the health care professionals, worked with the associations representing some of society's most vulnerable and read the heart-breaking correspondence from caregivers. Each of these groups came to me, desperate for some advice to help them manoeuvre through the legislative maze confronting them. Today, as Minister of Health, I am pleased to tell them that relief is on its way. Let me begin then by addressing up front some of the salient changes that this government is introducing in Bill 19.

The requirement for formal rights advice of the Consent to Treatment Act has been removed. This government has a fundamental belief that health care professionals will act in the best interests and according to the known wishes of a patient. Rights advice can be discussed among health practitioners, individuals and their families in a way that is appropriate in the circumstance. However, I understand that this section of our new act could be somewhat problematic and certainly will be the basis of discussion here at committee. So I'm going to be following with great interest the comments presented to this committee concerning these issues over the next few weeks, including comments made by groups such as health care professionals on how they will ensure that patients found to be incapable of consenting will receive basic information about the consequences.

There will continue to be an exception for psychiatric inpatients. Psychiatric facilities are a special case, partially since many patients are admitted against their will by civil committal.

This legislation will hold the advance directives of an individual and existing powers of attorney with the highest regard. We recognize the importance of abiding by such wishes. We recognize the importance of keeping

government out of personal matters that have been decided by an individual in concert with those central to his or her life. Only in situations where someone has absolutely no such connection will the state be allowed to step in.

Family members will not be required to make a formal statement before consenting to or refusing treatment for a loved one as was the case with the Consent to Treatment Act. We have taken significant steps to revise the previous government's legislation to allow the family to make substitute decisions for a loved one without unnecessary bureaucratic delay.

The new Health Care Consent Act gives family members clearer legal authority to make decisions for their incapable loved ones without the unwarranted interference of the state.

We have made important clarifications to the definition of treatment by exempting routine examinations, simple diagnostics and routine activities that encompass the day-to-day caregiving in facilities. The result is that care can be provided promptly.

Under the new act, a health care professional will be able to make required adjustments to a treatment without seeking repeated consent from a substitute decision-maker. This represents an important streamlining of the current process. The current repetitiveness of the process is frustrating to both families and providers.

As well, the new legislation will allow one health practitioner on behalf of a team of other professionals to propose a plan of treatment and ensure consent is obtained. The current legislation made this sort of process a bureaucratic nightmare.

We have introduced changes to ensure that treatment may begin promptly after the Consent and Capacity Review Board has confirmed that an individual is incapable. Only when an individual wishes to appeal the board's ruling will treatment not ensue directly. This is a significant amendment. It means that the mandatory seven-day waiting period which existed regardless of whether the individual intended to appeal has been eliminated. Again, this requirement of the previous act represented an unwarranted delay in treatment.

We have established a workable, streamlined process for admitting an incapable person into a care facility and for dealing with personal assistance issues that might arise in a facility. Such a process is completely missing from the Consent to Treatment Act, putting some of our most vulnerable citizens in a perilous position. In this way, the valuable principles of the Health Care Consent Act apply to more than just health treatment. This means that families will rarely have to go through lengthy and costly court processes to become guardians of their incapable relatives.

These examples illustrate the problems of the previous legislation that we have addressed, and I am confident that they represent significant and meaningful changes to the act. These changes will more realistically reflect Ontario's health care system. They will continue to honour people's wishes about treatment, such as their living wills and advance directives; keep the government out of family matters and strengthen the family's role; reinforce the positive role of health care providers;



eliminate needless delays for treatment of incapable people; and achieve a better balance between individual rights and the need for care and treatment.

Overall, this new approach, along with the changes to the Substitute Decisions Act and the repeal of the Advocacy Act, strikes a better balance between individual rights and the need to provide assistance, care and treatment for mentally incapable people in this province.

**The Chair:** We had scheduled to go immediately to opposition statements, and I'm going to suggest that we have a question period first and then proceed to the statements. Is that satisfactory? We have all three ministers here and I don't know their schedules. I don't know how long they can be here. If we wish, we could start off that way.

**Mrs Caplan:** How much time will we have?

**The Chair:** We've only got 20 minutes left but we do have one extra minister, so possibly there is some flexibility; say, the next half-hour altogether.

**Mrs Caplan:** So how much time will our caucus have?

**The Chair:** Ten minutes, including your statement. I don't know how long your statement is.

**Mrs Caplan:** Do I understand you're saying that we'll have 10 minutes, including all the questions we have to ask the ministers?

**The Chair:** It depends on how long your statement is. We're obviously going to go over the hour that is allotted here.

**Mrs Caplan:** Are the ministers leaving at that time or will they be available to answer some questions?

**Hon Mr Wilson:** We would be happy to answer questions for the next half-hour and then we have to leave.

**The Chair:** Okay, 10 minutes each, then, and the statements will come after that.

**Mrs Caplan:** There are a number of questions that this very complex legislation raises. I particularly want to thank the Minister of Health for giving us copies of his statement and thank the other ministers for appearing. It is very frustrating to know that in total, our caucus is going to have just 10 minutes to ask those questions. In the last go-round, the questions that we placed on the record—I'm talking now about Bill 26—were never answered before we got into clause-by-clause deliberations.

I'll just start really with one comment. I was looking very closely at Jim Wilson's face when he read the following words, which I agree with, to see if he was blushing, and he was not and he should have been, when he said how important it was that we have legislation—"We have a responsibility, therefore, to bring forward clear, concise and thoughtful legislation. Confusing legislation leads to an obscuring of policy goals and, in the end, leaves those we sought to protect unprotected." I would suggest to him that that's a very valid statement. I agree with it completely and it's probably the reason he chose not to appear to discuss Bill 26, which was anything but concise and thoughtful and having defined policy goals.

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I'm going to lead with the very first and most important question that I think this legislation raises. There are

several, and I will have questions for each of the ministers. But particularly under the issue of confidentiality, my concern is that we see problems here again, and there are some very specific places where I ask if you share my concerns. More than that, I'd ask if the privacy commissioner was consulted on Bill 19, if you have anything from him in writing where he has expressed his concerns and if you'd like to comment on the fact that when any individual—I'm going to now ask that you address section 60 of Bill 19, which introduces clauses 90(e.4) and (e.5).

This permits, according to my reading, any member, anyone actually, if they're under the Regulated Health Professions Act—so that's any and all professionals, anyone subject to the Mental Health Act and anyone subject to the Long-Term Care Act, and as I read it, it goes even further and says notwithstanding any act—any "person who has made or has stated in writing an intention to make an application to appoint a guardian of property or guardian of the person"—that is either for financial or for health care decisions—"if the information is relevant," all of the individual's health records can be disclosed to that unnamed person who doesn't even have to tell the individual that he or she has applied for guardianship. Is that how you read this legislation?

**Hon Mr Harnick:** Let me just, at this point, go back to your references to the privacy commissioner, because we have spoken to the privacy commissioner about this very issue. There will be regulations pursuant to this act that will deal with this that are being drafted and will be the subject of discussion with the privacy commissioner so that we don't have a difficulty later on.

Specifically, we are addressing that with him, and as the public guardian and trustee deals with these sections, there will be confirmation that our regulations comply with what the privacy commissioner is looking for.

**Mrs Caplan:** Did you have a discussion with him before the legislation was drafted or after it was already tabled?

**Hon Mr Harnick:** I believe that those who were drafting the legislation spoke with the privacy commissioner.

**Mrs Caplan:** Be careful. I spoke to him.

**Hon Mr Harnick:** Well, I'm telling you I believe that those who were involved with the intimate drafting of the details in the public trustee's office have spoken with the privacy commissioner. That is what I am advised. They will be developing regulations, as I indicated, that will deal with the concerns he has and they will be developed in conjunction with him.

Certainly, if you have recommendations and concerns about this, that's why we're going to be here for the next four weeks, so this doesn't have to begin as an adversarial process. We're very happy to listen to the comments you have. I know that you, as a critic, have been very critical of a lot of the areas that these acts deal with. You were critical of the previous government's legislation; I have no doubt that you will be critical of certain areas in this legislation, and we're interested in hearing what those are.

This is not an exercise in adversarial process, nor is it an exercise to see if we can trip up the draftsman, but



what we want to do is produce a piece of legislation that is going to be good for the public.

**Mrs Caplan:** I'm pleased to hear that. My question is to the Minister of Health. The consent-to-treatment portions are yours. Did your officials meet with the privacy commissioner prior to the tabling of the legislation to discuss concerns about privacy?

**Hon Mr Wilson:** Privacy has been a topic of a great deal of debate with the privacy commissioner. In the context of an overall health care act, as you'll note that during Bill 26, when the privacy commissioner first came forward, his real plea was, and I gather this plea has been going on for a number of years, that the province enter into and the Ministry of Health in particular enter into a comprehensive privacy act for health records. So within that context, we will be continuing to talk to the privacy commissioner.

**Mrs Caplan:** So the answer is no. No, you didn't meet with him before the legislation was tabled.

**Hon Mr Wilson:** Not specifically on section 60, which is disclosure of information, which will go through the debate under Bill 26 again and in the end the privacy commissioner did point out some need for improvement. Also, I made the commitment to work with his office and do a comprehensive health statute, which we probably will need anyway as we move towards a smart information system.

**Mrs Caplan:** There are many parts of this bill that my caucus and I have some concerns about and there are many parts of this bill that we think are an improvement over what was existing. However, if I could make the following statement to the ministers who are here, as I ask the question—this is my question; I'd like all three to answer it—are you willing to table a list of all of the organizations that have an interest in this legislation that you consulted with formally or had your ministry consult with prior to the tabling of the legislation? That would be very helpful, so we can see your formal consultation, who you talked to, who had input to the legislation. Are you willing to table that list? We know there was no consultation on Bill 26. I'm assuming there is on this one.

**Hon Mr Wilson:** You're wrong on Bill 26 and you were wrong every time you said that in committee.

**Mrs Caplan:** They all said no, Jim.

**Hon Mr Wilson:** Secondly, do you want the consultation that goes back over 15 years with respect to this legislation?

**Mrs Caplan:** No, since you've been Minister of Health.

**Hon Mr Wilson:** Some 200 groups were consulted in 1992.

**Mrs Caplan:** Since you've been Minister of Health, before this bill was tabled, who did you talk to?

**Hon Mr Wilson:** Hundreds of individuals have appeared before committees on this legislation.

**Mr David Tilson (Dufferin-Peel):** Let's hear the answer.

**Mrs Caplan:** Okay.

**Hon Mr Wilson:** We've been spending our time in the last six months talking to many, many of those groups.

**Mrs Caplan:** Will you table the list of who you met with and talked to about this?

**Hon Mr Wilson:** No.

**Mrs Caplan:** I find that strange, because I'm now going to have to ask those who come if they were consulted and ask anyone out there who was a part of the consultation to phone us and let us know.

**Hon Mr Wilson:** Elinor, you seem to want to make a fight out of every piece of legislation.

**Mrs Caplan:** I don't want to fight.

**Hon Mr Wilson:** As the Attorney General said, you're setting up this to be another adversarial committee—

**Mrs Caplan:** It's a reasonable question.

**Hon Mr Wilson:**—when we're dealing with very serious health legislation here.

**Mrs Caplan:** I agree with you.

**Hon Mr Wilson:** The intent of all legislators, I hope, including yourself, is to get this right. That's what we're working towards here. Again, you're starting today with the same adversarial approach you took in the past, and it's not that helpful.

**Mrs Caplan:** Listen, I want to make good law. That's why I'm here.

**Hon Mr Wilson:** I meet with dozens of people every week, and if you'd like copies of our schedules, I'm sure they're a matter of public record.

**Mrs Caplan:** If you'd like to stay and answer questions to make this better law, let me tell you something: We would be happy to have you here, just as we would have been happy to have you at Bill 26 to do that, to make it better law. If you want to know if I'm still upset about that, the answer is yes, I am, and so is Mr Ramsay and so is Mr Grandmaître.

**Hon Mr Wilson:** So am I, with the misrepresentations you made on Bill 26 across this province. I'm quite angry about that too.

**Mrs Caplan:** Yes, we're angry about the way you do business, but this is important legislation.

**Hon Mr Wilson:** It would be helpful if we talked about the content of Bill 19 and not the process.

**Mrs Caplan:** It certainly would.

**Hon Mr Wilson:** Because you bogged down Bill 26 with process questions which weren't that helpful in terms of trying to improve the content in some cases.

**Mrs Caplan:** It would have been helpful if you had been willing to come to committee so we could have dealt with some of the contents.

**Hon Mr Wilson:** I was at committee, as required as a minister of the crown.

**Mrs Caplan:** Let me tell you something.

**Mrs Caplan:** I'm going to ask the other ministers if they would be willing to give us a list of the groups and organizations that they consulted with prior to the drafting of this legislation and I would like to ask them, if we place questions that we will not have time to ask you personally, if we place those on the record, will you each give us your commitment that those questions will be answered prior to the clause-by-clause discussions being completed on this bill? I don't think that's unreasonable. Two questions: Who did you consult with? Will you tell us? Second: Will you allow us to have our questions answered before the bill is rammed through?

**Hon Mr Harnick:** Certainly, I've been here for five years and I don't recall the last government ever coming

to tell us who they consulted with when they drafted a bill. I suspect that when you were Minister of Health, you never sat in this chair and talked about who you consulted with when you drafted a bill.

**Mrs Caplan:** That's not true. Yes, I did.

**Hon Mr Harnick:** I would like to see it in Hansard and I'd like to see the lists that you laid out. At any rate, I'm not prepared to tell you who we talked to in the drafting of this bill.

**Mrs Caplan:** That gets off to a good start.

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**Hon Mr Harnick:** The bill speaks for itself, and the bill some people will like and some people will have some criticisms over. What we're here to deal with is to finalize this bill in a form that's the best bill possible for the people who have to access, at least under my part of it, the substitute-decision-making rules.

This bill, at least from the point of view of the Substitute Decisions Act, is responsive to some very significant criticisms made about the bill when the bill was passed. That's the response. You will hear from people—because I've seen the list of the people coming—many of whom have been consulted over a long period of time dealing with this particular legislation, which I think Mrs Boyd will tell you was about 15 years in the making and study. It's a very controversial bill, and for every person who probably says that it's a good bill there's a person who says it could be better. We're going to listen to all of those people and their advice and see if we can come up with a bill that is responsive and good for the people of the province of Ontario.

In terms of other questions you might have, I'm interested to hear what those questions are. Of course, if they're valid questions that don't have a motive that is anything but making this bill better, I'm delighted to answer those questions.

**Mrs Caplan:** My motives should not be questioned.

**Hon Mr Harnick:** Let me finish, please. I'm sure that officials in all three—

**Mrs Caplan:** On a point of order, Mr Chair: He cannot question motives.

**Hon Mr Harnick:** I'm sure that people in all three ministries—

**Interjection:** He can do whatever he wants.

**Mrs Caplan:** He cannot.

**Hon Mr Harnick:** —are going to do their very best to answer the technical questions that you have. I know and you know that we're both here for the same reason.

**Mrs Caplan:** I hope so.

**Hon Mr Harnick:** We want to create the best bill that we possibly can. I'm interested in your criticisms and your improvements and your amendments, and certainly I hope that if you have questions, if we're able to answer them, we will.

**Mrs Caplan:** Good legislation comes from talking to people. Why won't you tell us who you talked to before you drafted the bill?

**The Chair:** I'm sorry, Mrs Caplan, the time is up. We're now moving on to the third party for questions.

**Hon Mr Wilson:** You can never win this battle because you give an exhaustive list of all the people you talk to and you always miss someone, and we're only

human. That's the game Mrs Caplan wants to play again—a process question.

**The Chair:** Okay, Mr Wilson. Mr Marchese.

**Mr Rosario Marchese (Fort York):** My colleague and I will be sharing the 10 minutes; I'll have five and she'll have the other five. I have a statement to make in my time. Because the ministers have had their time to make some statements, I'd like to do that as well. There will be plenty of time for questions as we go along, with all the deputations that will come in front of this committee, so we'll leave that to then.

My beginning comment has to do with the government members talking with respect to the employment equity bill, how it was draconian, how it was intrusive, how it had a quota system that was repulsive to all of you and that's why you changed it. Then you introduced Bill 26, which in my view and the view of many is the most unprecedented draconian bill that we have ever seen, is the most intrusive bill that we have ever seen; and not only that—it had quotas on where doctors would go. It's incredible how you could on the one hand say, "We're going to get rid of a bill that was intrusive and now we're going to get rid of the Advocacy Act because it's intrusive," and you have the gall and the audacity to introduce Bill 26, which has the worst elements of what is draconian and intrusive that we've ever seen and has quotas.

I want to give that context so that those who are watching understand the contradictions that we have to endure in opposition. I want to say that if we, the NDP, can be faulted for anything, it's that we consulted too much, with too many. The list of the people whom we consulted on a number of bills is lengthy. I think you know that.

Our role as opposition, of course, is to be critical of the positions you put forth, and from time to time we believe we have positive things to say and positive changes to suggest. Then it's up to you as the government to determine whether you think they're positive or not. But it's our job to listen to the deputations and at the end of it say, after hearing all of that, "What have they said that we can bring to your attention that we believe is correct, and that based on that you should listen to them, you should change your legislation to reflect that?"

With respect to the Advocacy Commission, I believe that you, Ms Mushinski, are wrong, that the cabinet is wrong and that this government is wrong in eliminating the Advocacy Commission. Of course, it's always a matter of opinion. That's why we have hearings and we're going to listen to many deputations that will speak to this and to the other changes to the Substitute Decisions Act and the Consent to Treatment Act.

I believe that when you have a population that's aging—and we'll have more seniors than ever before in the next 10 to 15 years—and when governments are under growing pressure, as we've seen through your government, to cut services unlike ever before, and when we're seeing financial assistance being reduced unlike ever before, the need for advocacy has never been greater. What you are now doing is eliminating the very institution, the very commission that could begin the work to give people, vulnerable people, dignity, the



autonomy that I think some of you want them to have, and their rights recognized and respected. I believe that flows a great deal from the Advocacy Commission. You obviously don't believe that. You believe that, through the various institutions that have existed in the past, they will deliver the advocacy that is necessary to protect vulnerable people. We don't think so. It was because of the failure of the system that we had in place that we put, as a former government, in place a commission that would deal with some of those problems. So I believe that you're wrong in doing this.

I like Mr Wilson's statement that says, "Yes, there's likely to be some disagreement about one or two things that we may have done, maybe more," and that you will be listening closely to what people have to say. I'm not convinced. We certainly didn't think that was the case through the hearings on Bill 26 in terms of you listening. Yes, you made a few changes, and maybe that's sufficient for the government—I'm not quite sure—but I hope that you will do exactly what you said, and that is that you will be listening. I'm assuming that holds for the other ministers in the government. Because there will be many deputations that will come forth that will say many things in disagreement with what you have presented. My hope is that if you see a pattern of disagreement that is great by a number of service providers, you will indeed reflect that through changes in your bill.

**Mrs Marion Boyd (London Centre):** I would say to you very clearly that with a very serious issue such as the protection of vulnerable people, it really is important for us to dedicate our efforts to making sure we've got the best possible legislation. If indeed there are changes in the processes and the administration of these provisions that in fact make it work better, particularly for vulnerable people, then I think you will find a lot of support from all parties, because I think there were real concerns about the cumbersomeness of some of the provisions that were there, although I would point out to you that the legal advice came from the same people you're getting your legal advice from. That's always a little puzzling. But the cumbersomeness is certainly something that all of us would like to see removed.

I'd like to say to the Attorney General that you and I know very well that your role is a little different from any other minister's, and that primary responsibility to protect the constitutional rights of individuals is a very special part of your job but is different from any other minister's. One of the concerns that I think we will hear from a lot of groups is around constitutional rights and constitutional issues; the lack of due process, for example, because of the assumption that families will always act in the best interests of people, that a family member can, on their own determination, determine that a person is suddenly incapable. I think we should have concern about that, and that really leads to a need for us to examine what the likely outcomes are going to be.

All of you have said, again and again, that the majority of families will act out of care and loving, and the majority of institutions, where people don't have families, will operate out of that altruistic sense as well. It may be that the majority do, but your job, sir, is to protect the rights of those where that does not happen and it's the

job of government to make sure that the processes are in place to protect those vulnerable people when their rights are being flouted.

I seems to me that, particularly in the area of incapacity, if we're not explaining to people what their rights are at each stage of the game, if we're not even letting them know—and this bill would allow someone to be declared incapacitated without their ever knowing. Yes, it would, and you'll hear many examples from people who will come and testify about that. If that can be shown to be true, I hope you will agree that we need to change the wording of the bill to ensure that doesn't happen.

**1400**

Similarly, in consent to treatment the whole purpose of consent to treatment is based on informed consent. One of the biggest complaints the consumers in the health system have is that there is a growing sense that they seldom get the kind of information they require. It seems to me that part of what we are trying to do with a bill like this that is trying to cover the whole continuum of how we protect people who are vulnerable within our systems is to ensure that the obligation is clearly there—not just our belief that the goodwill of physicians and other health care professionals will call upon them somehow to give rights advice, but that we find a mechanism to ensure that it is in fact a dereliction of their professional duty not to provide that kind of advice about the rights the patient has when they're going to be declared incapacitated and the consequences of any treatment that is being proposed to go on. That of course applies to the substitute decision-maker too, that informed consent has to also inform the substitute decision-maker of the likely consequences of a decision.

So I think as we go on it will be really important for us to listen to the experience of those who've been working with the act as it has been in place for a very short period of time, what the public trustee and guardian's office has found to be statistically the case, what the Advocacy Commission has found to be the kinds of cases that they're dealing with and where the problems exist, what the different advocacy groups fear and examples of why they fear it, so that as we work through this we can meet some of those fears so that the confidence is here in this act. It's a truism to say that all of us are only temporarily abled and temporarily have capacity. So it's in all of our best interests to make sure that the legislation that's on the books is legislation that all of us would want to live with if we were to be substitute decision-makers or attorneys on behalf of somebody but also if someone were to take that action for us.

As we go through, I'm delighted to hear you say you want to listen to what is happening and that you're prepared to make some changes if there are issues that don't meet what you say are the principles of what you want to do, because quite frankly I think some of the streamlining has really cut out a lot of the protections that were meant to be there in the first place, and we really need to look at that very carefully.

**The Chair:** Mr Marchese and Ms Boyd, you did it exactly in five minutes each. I congratulate you. Questions from the government members.



**Mr Tilson:** After the legislation was passed by the former government, one of the greatest fears of people in the public was that when they had power of attorney, when someone had named a family member or any individual an attorney, the government was going to come and overrule all that, any sorts of decisions that they were going to make. So it really didn't matter what the individual did or what the individual requested be done; the state was going to come along and overrule all that or interfere in the process of that individual's life.

Now, Mrs Boyd of course has commented that there may be situations where individuals may take advantage of that situation, notwithstanding that that was a request of the individual who made the power of attorney. That's a reasonable question, notwithstanding the fact that I have quite frankly have a little bit more faith in our families in this province than the suggestion that all families are going to take advantage of—and I'm sure that wasn't your intention.

**Mrs Boyd:** I didn't say that.

**Mr Tilson:** But that's the way it came out, that individuals would take advantage of someone who had become incompetent. I wonder if any or all of the ministers could comment on that issue, to assure the people of this province that that situation simply won't happen, that the state will not be interfering in our lives like the previous legislation had put forward.

**Hon Mr Harnick:** Certainly that was reflected, I hope, in the remarks I made earlier. That is quite simply why we are looking to re-establish the family as the prime area for substitute decision-making, to expand the role of families in the substitute decision-making process.

As well, and you touched on this because it was very important in, certainly, the determination that we had to make significant amendments to this act, and that's the fact that once an individual takes the steps to appoint someone as their substitute decision-maker, it was very disconcerting to people all across this province to know that under certain circumstances, even though they'd made that power of attorney, there was a chance that the government could step in and take over in spite of their wishes.

We very specifically deal with that in this legislation, to ensure that can no longer happen, that there will not be that override of the government to take away the decision-making process that someone has entered into in the event that they should become incapable. That's another matter that was dealt with very specifically within this bill.

I'll be very interested to see, to follow up on the remarks of the member for London Centre. We want to know whether the rights advice that I believe is sufficient can be conveyed in the way that we've set out in this act. I believe it can. I believe that is fundamental to giving back to families the right to carry out the wishes of their loved one. That's very much what has motivated the changes we have made in this bill.

If there are issues about whether we're protecting or not protecting vulnerable people, I'm sure that some of the legal minds—and I've seen the list of people who will be presenting to this committee from bar associations and advocate groups that specifically have the legal

background and training to talk about whether this properly protects people. I've looked at the list and I've read the commentaries. I'm quite certain that this act does provide the necessary protections, while at the same time giving back to families the opportunity to carry out the wishes of a loved one. That's what this bill is all about.

**Mr Tony Clement (Brampton South):** I just wanted to follow up on Ms Boyd's comments. There was a bit of an interaction there when Ms Boyd characterized the bill as leading to a situation where people would not be advised if they are subject to substitute decision-making, if I can paraphrase what Ms Boyd said. I sensed a vigorousness in your denial on that front and would like you to elaborate on that for the record today.

**Hon Mr Wilson:** Perhaps, Mr Chair, I should comment on that because it is an area—and I singled that in my remarks. Ms Boyd can certainly speak quite capably for herself, but in terms of the Health Care Consent Act, although Ms Boyd did make these comments under her SDA comments, certainly there has to some discussion. You're going to hear from the colleges of the professional health care providers, like the College of Physicians and Surgeons and others, which will strenuously argue that we shouldn't have too rigid a regime with respect to the provision of rights advice and information to persons who are found incapable. The act is very clear in the cases of incapacity and admission to long-term-care facilities, and also psychiatric facilities, in the province.

The act is not as clear with respect to rights advice in all other circumstances. Somebody's in a car accident, arrives dazed at the emergency room, there are things to do in terms of treatment that may fall outside of the definition of treatment in emergency that's contained in the act, and therefore a frank and open discussion has to be had as to what are the best mechanisms to ensure that people are made aware of a finding of incapacity and their rights to appeal that finding of incapacity.

1410

But again, I would ask members to have an open mind. You're going to hear strenuously from colleges that say, "We'll be back to square one with the NDP's legislation if we put too severe a regime in there." You'll hear others saying, "We can't trust doctors, as part of their clinical practice, to ensure they properly inform their patients." You will hear suggestions made that perhaps the rights adviser or the person who is to provide information to an incapable patient should be someone who's not part of the clinical team.

We as cabinet ministers want to hear, and I think the people of Ontario want, this full debate. It's one of the areas where certainly we'll be entertaining suggestions from the committee. So perhaps that's what you were saying, that it's not foolproof rights advice in every case, but I tell you, following on what the Attorney General said, anything, in my opinion, is better than having strangers called advocates, an army of advocates, come in between you and your family. So we need to find a way to ensure that people are informed of their rights and the processes that derive from those rights, at the same time not having put into the process another layer of bureaucracy and expense and strangers who aren't part of the

clinical team or part of the setting. That's what we're attempting to straighten out through this legislation.

**Mr Tilson:** I have a question to Ms Mushinski and that is with respect to the Advocacy Commission, which is an agency operating at arm's length to the government and which provides advice to mentally ill people. My understanding is that the costing projections of this commission were going to be between \$30 million and \$100 million. This legislation came into law, I believe, April 1, 1995. Can you tell us how much government money has been spent on this commission to date and, secondly, what they have been doing?

**Hon Ms Mushinski:** I can tell you that they haven't been advocating advocacy. The only thing that they have been doing is providing rights advice, to the tune of \$18 million. They're spending on rights advice approximately \$500,000 a month. The Advocacy Commission itself has not done anything other than rights advice for the last 12 months. They have not done anything about advocacy and the rights of vulnerable people at all, other than providing rights advice and, as you suggested, going into people's homes. So it's a professional bureaucracy, and it was the whole intrusive nature of that bureaucracy that a lot of the advocates themselves have been so outspoken about. That's the key reason we've repealed it.

**Mr Tilson:** Can you tell us what communication the commission has had with the your ministry?

**Hon Ms Mushinski:** In terms of the consultation process, my ministry has begun consultations with consumer groups, service providers.

**Mr Tilson:** No, I didn't mean that; I'm talking about the commission.

**Hon Ms Mushinski:** The commission itself? Well, one of the designers of the current Advocacy Commission—and former adviser, of course, to Bob Rae—David Reville, has made several suggestions on future directions for advocacy. My understanding is that he did have a press announcement this morning.

**Mr Tilson:** I think he's paying us a visit tomorrow, as a matter of fact.

**Hon Ms Mushinski:** My ministry has begun consultations that include Mr Reville. His comments will be considered along with all of the other comments that we receive in the next few weeks.

**The Chair:** Thank you, ministers. That concludes your portion. You are welcome to stay, but I'm sure your schedules demand your presence elsewhere. The loyal opposition has an opportunity to make a statement.

**Mrs Caplan:** I was very disappointed with the answers and obviously the attitude of the ministers who weren't prepared to share with us the consultations that they've made. I would like to say that I believe, as a member of this Legislature over almost 11 years now, that my record is a good one when it comes to wanting to make good laws, and it's a good one whether I was a minister of the crown or whether I was a member of the official opposition, I have always felt that my goal and my role was to try and improve legislation. I was proud of the fact that as a minister of the crown I brought forward legislation that was very specific in its goal, and ensured there was a sense of consultation and a willingness to meet with and discuss the objectives of the legislation.

I'd like to begin with just a few thoughts on Bill 19. It is very complex and important legislation. It deals with issues that affect people directly, not only individuals or ordinary people across the province; it has an impact on those who provide service in the health sector and those who receive service from health providers; it also has an impact on individuals who want to plan for their future and it gives them the right, which I support absolutely, to decide who will decide when they are unable.

How much time do I have? I would just like to check that out because I want to leave some time for my colleagues. How much time will there be for this statement, just a few minutes?

**The Chair:** Approximately 5 minutes each at most.

**Mrs Caplan:** Each of my colleagues, or for each caucus?

**The Chair:** Each caucus I would think.

**Mrs Caplan:** Each caucus. I guess there's not going to be time for my colleagues, but there will be as we proceed, I hope, an opportunity for us to get this on the record. This is the concern I have. As much as I'd like to spend some time on each of the pieces of legislation, I'd like to deal with the underlying ideology.

The previous government, the NDP, I believe was well intended when they brought forward legislation dealing with the issues of substitute decision-making, consent and advocacy. It is true that those issues have confounded all of us because they deal with vulnerable people and the needs of society to catch up with all of the things that have been happening over these many years: new technology, keeping us alive longer and longer, and people wanting to have more say about that.

It is true we have seen reports, the Manson report, the O'Sullivan report and the Fram report, that gave governments very specific advice. It is also true, as a member of a government, that there were three pieces of legislation frankly ready to go, and I remember calling across to Evelyn Gigantes who was the Minister of Health, saying to her: "Pull the legislation out of your drawer and get on with it. It's important that these things be dealt with. We will be helpful and supportive."

The legislation the NDP presented was very different from the legislation I had worked on and I was critical of it. They started with an assumption that all providers, all the professionals out there, were not to be trusted. That was their ideological bent. They also came at it with an assumption that all families were all—even though they set in place the kind of very bureaucratic structures that made it difficult for people to be protected. Their assumption was that intervention is good, and that families and providers could not be trusted and that the social structure of our society, which consisted of either individuals—and the state really excluded families from having an automatic right to participate.

However, the Conservative government I think comes at it with almost a mirror image, the opposite approach, that is equally of concern to me. They start with the assumption that all families and all providers are good. If that were true, then the Fram work, the O'Sullivan work, the Manson work and the fact that we daily hear stories of elder abuse and child abuse, and of vulnerable people in institutions being abused by families and by pro-



viders—it's real. So your assumption that all families and all providers are good is faulty.

I agree with your ministers when they say—the majority—that the reality is this legislation doesn't reflect that. This legislation starts with an assumption that all families and all providers are going to act in the best interests of the patient, or of the individual who is incapable. I think it's obscene that you have a piece of legislation that does not require that an individual who is found to be incapable by a provider has no right to be informed that they have been deemed incapable.

1420

Think of it, Helen. Think of it, all of you. You are found by a provider to be incapable of making a decision about yourself. They don't have to tell you. They can go to your next of kin and do it. You never have to be told that you've been deemed incapable. I don't think that protects the vulnerable in our society. This legislation would allow that to happen. I think that's wrong and it should be fixed.

Certainly there are those out there who might want to say that I'm incapable. Let them have to tell me. Let them have to at least tell me so we can argue it.

**Mr Frank Klees (York-Mackenzie):** Let's have a vote.

**Mrs Caplan:** There's something else they should have to do if they believe I am incapable. I think they have an obligation to tell me I'm incapable, that they've decided. They also have an obligation to let me know that there is a process for appeal. That is not in this legislation.

I believe this legislation as it stands today is significantly flawed and does not protect the rights of individuals. It makes this assumption that all families and all providers are going to act in good faith. I think that has to be fixed.

I'm very concerned about the confidentiality provisions of the legislation. I raised them this morning, and so I'd like to move while I have the floor that this committee invite Mr Tom Wright, the commissioner of personal privacy and freedom of information. I believe there are two slots available tomorrow, 4:30 and 5 o'clock, that have not been filled. I spoke to him this morning. He is available to appear and I'd like to formally request that he come before this committee to give us some confidence that he is working with the government and that those concerns can be addressed.

**The Chair:** Thank you, Mrs Caplan. We have a motion on the floor, properly moved by Mrs Caplan, that we consider calling the privacy commissioner before us tomorrow in one of our vacant time slots. Is there any discussion in regard to the motion?

**Mr Marchese:** It's a good idea, Mr Chair.

**Mr Clement:** Could I just ask in terms of procedure, Mr Chairman, there are two time slots that were available for tomorrow that have not been filled. Is that correct?

**The Chair:** The clerk will have to check on that.

**Clerk of the Committee (Ms Donna Bryce):** I'll check to make sure they're still open. It's the committee's wish if they want to add an extra time slot if those are full.

**Mrs Caplan:** I think it's important that we hear from him. If, as you've heard the minister say, they're interested in making this law better, you certainly could have

no objection to having the commissioner come and share with us—

**The Chair:** We don't know at this moment whether or not they are available, but assuming they're available, one of them, is there any further discussion?

**Mr Marchese:** If there is no slot tomorrow, then the other option is either to create another slot and/or if there is another opening the following day, he could come the following day. I'm sure that between your office and the clerk that can be solved without too many problems.

**Mrs Caplan:** I want to amend my motion to include that. I think that's friendly. We want to have him here over the next couple of days.

**Mr Tilson:** I have no problem as long as there's a time slot available.

**The Chair:** The clerk has advised that the two are available tomorrow, assuming he is available.

**Mr Marchese:** Assuming he's available, that's right.

**Mr Tilson:** For a half-hour slot, sure. To be fair to Mr Wright, I don't know how much time he needs to prepare for that, but I guess if he's able to come and make some comments, that's fine with me.

**The Chair:** The Chair is watching.

**Mr Marchese:** We'll leave it to you.

**Mr Klees:** I'd like to suggest that in the event timing precludes him from attending here, at least the motion include an invitation for him to submit something in writing as to his opinion.

**Mrs Caplan:** He said he's available. He can come.

**Mr Clement:** So you've already invited him.

**Mrs Caplan:** What's the point of saying that I'd like him to come, that there's time available, if he couldn't be prepared? So I called him this morning and I said, "Would you be able to come?" He said yes. I didn't invite him.

**The Chair:** Excuse me. Mr Klees, did you mean to amend the motion by your comments?

**Mr Klees:** I wasn't aware that the invitation had been extended and accepted, so I'll withdraw that.

**The Chair:** It's all basically whether he can attend. We have the time slots. I think that's the end of the discussion.

All those in favour of the motion? Carried.

We will arrange to have Mr Wright attend tomorrow. Thank you for the excellent suggestion, Mrs Caplan.

Does the third party have any further presentation you'd like to make?

**Mrs Boyd:** Yes, just very briefly. I would really like to see, as I said to the three ministers, that we do our work in a very clear and careful and respectful way. We are going to hear very differing views from the consumer side and the provider side on many of these issues, and it seems to me that one of the things the original legislation attempted to do was to find some balance between those views, which are quite extreme.

If indeed it is the view of the government that we did not achieve that balance, then what we really are trying to do here together is to try and find where the weaknesses were and to strengthen those, because one of the things we ought to be very aware of is that we are one of the first jurisdictions to try to provide this kind of protection to vulnerable people, that there isn't a lot of experience to draw on, certainly not in Canada but in



other jurisdictions as well, and that we don't always get things right the first time around. As is always true, I think we hear more from those who are the recipients of services, the ones who have that intimate experience on both sides of the question, and we need to be listening and balancing very clearly.

I will say that many of the professional comments from both the legal profession and the medical profession that we heard about this bill were, quite frankly, in my view, efforts on the part of those who have always held the power in this kind of decision-making to try and maintain that power—to try and really look at the ability of consumers of services, those who are vulnerable themselves in speaking out, and I think we will hear very strong representations from some of the consumer groups, some of the advocacy groups, to that effect.

I hope we will be able to hear where that discomfort comes in, where that concern is about whether or not the rights of those who are most vulnerable are being respected, because it really behooves us as a government that is on the cutting edge of this kind of legislation to try and ensure that in our efforts to streamline it we don't destroy our ability to provide that kind of protection and those kinds of rights.

In response to the concerns that have been raised around families always being wrong or providers always being wrong, that is not the point and has never been the point. It is not my belief that when we talk about protective rights legislation, we are ever talking about the majority. That's not what we're here for. The job is to protect that minority of cases where the vulnerable are not protected by those we might want to assume will protect them or where there's a major conflict of interest between those who are in a position of power over vulnerable people, whether they're family or providers.

One of the things we will also hear from the deputants is this issue of vested interest and conflict of interest in the decision-making, and I think we need to listen to that very carefully. When you are looking after a severely disabled or frail elderly person in your home and that person is a member of your family, you may well have difficulty—people tell us all the time when they come to see us that they do—distinguishing between what is in their interest and what is in your best interest or the family's best interest, and that surely is a conundrum many people face.

What we have to be sure of is that in this provision of families having an ability to make a determination, having an assumption that somebody is incapable and therefore starting to make decisions on their behalf, that is really made out of the best interests of the vulnerable person and not done as a result of the very often emotionally wearing situation of the caregiver.

1430

When we went through the legislation the first time, this issue of caregivers and who could be, as a caregiver, a substitute decision-maker was a very important issue and we did allow those who are immediate family to be a substitute decision-maker, even when they were caring for their loved ones. It seems to me that when we go to the next remove of caregivers who are often in a paid position or who have a vested interest in the property of the person who is vulnerable, that whole issue needs to

be looked at again. I think as we look at the new bill, we need to be sure that that protection has not been lost.

I would emphasize we're only talking about a minority of cases, but all this kind of legislation comes forward because those minority of cases are very tragic. We probably will hear more stories, but there have been many stories about very tragic instances where people have been institutionalized against their will, not always in their best interests, where people, as in the recent case that we all heard last week in Alberta, have had medical procedures performed on them as a result of decisions made by substitute decision-makers that ought never to have been made. We have to be aware that those things happen, and that why we have this kind of legislation is to prevent those things from happening, not because we assume every health care provider or every family member is going to act inappropriately.

I think again, Mr Chair, that I would really emphasize that it is going to be important for us to be very attentive listeners to the realities that come in front of us. I think that many people who have been critical of the legislation are equally wanting to protect the same vulnerable people and that it is important for us to listen to the different solutions that may come forward that may or may not accord with the bill that's in front of us. Thank you.

**The Chair:** Thank you, Ms Boyd. Actually you've run out of time, but could I permit Mr Marchese one minute just to wind it up? Thank you.

**Mr Marchese:** Just a quick remark. I wanted to respond to Ms Caplan's characterization of what the NDP assumed. She says the NDP assumed that providers and professionals were not to be trusted and also that all families were not good. That characterization, I think, is incorrect.

I think the characterization that Ms Boyd speaks of is the one we were concerned about, and that is, in those situations where some families are not treating the ones they should be loving well, how do we deal with that? How do we deal with the cases where individuals may not have a family and then you fall into a problem? How do we deal with a situation where yes, in some cases, some providers may not be dealing very well with those who are in their care?

The point of it is that you need some protections for those vulnerable people, and that's why our bill, we felt, did that. So the assumption is that sometimes the system fails us, but we need within a bill enabling legislation that protects those vulnerable people.

**The Chair:** Thank you. We are now going to hear from the Ministry of Citizenship, Culture and Recreation.

Because of the extra minister, we are running approximately one half-hour over and it means that if we could restrict the presentations and questions to 15 minutes each, we'll finish by 5 approximately.

#### MINISTRY OF CITIZENSHIP, CULTURE AND RECREATION

**Ms Luby Carr:** Good afternoon. Thank you. I'm going to give a very brief overview of the original Advocacy Act, Bill 74.

The act was designed to promote the rights, dignity and autonomy of people who are vulnerable due to illness

or disability by providing them with rights information and advocacy services. The act was designed to offer representation and support to people who are vulnerable. Advocates operating under the authority of the independent Advocacy Commission were to be available to inform vulnerable people of their rights and opinions, tell us others what the person's views are and challenge the practices and policies that affect vulnerable people.

This was to be done through the provision of rights advice and other advocacy services. Currently only the rights advice piece and intake and referral are in place. Vulnerable persons are defined as those who are 16 years of age and over and because of the conditions described above have difficulty expressing or acting on their wishes.

"Advocates" in the legislation were defined as those who were certified by the commission. That could be either commission employees or designated community agencies. The commission itself in the act provides for 13 members and is required to table an annual report to the minister.

The commission is charged under the act with carrying out the functions, including minimum qualifications, standards, a code of conduct and training programs for advocates. The commission is to authorize and monitor the provision of advocacy services by individuals and community agencies. It's an arm's-length agency, although the funding is within the ministry itself.

The act provides for a family and service provider advisory committee, which is to advise on the impact of advocacy services provided by the commission on families of vulnerable adults and health and social service providers. It's an unscheduled agency and has five members and a chair. The committee consults with and advises the commission on its policies and procedures and comments on the effect of advocacy services.

Briefly, there are four kinds of advocacy services in the legislation. There's rights advice, which you'll hear more about. The Advocacy Commission must provide rights advice and other advocacy services respecting the Advocacy Act itself, the Consent to Treatment Act and the Substitute Decisions Act. It has been providing that rights advice since April and will continue to do so until the bill is repealed.

Individual advocacy: Instructed advocacy describes situations where the vulnerable person can express their wishes but doesn't seem to be able to get those wishes across, so they can instruct an advocate on what those wishes are. Then there is non-instructed advocacy, in which case the individual vulnerable person has expressed wishes perhaps before but is unable at this time to instruct an advocate.

Systemic advocacy is also described in the legislation as bringing about systemic changes at the government, legal, social, economic or institutional levels.

The linking of the three pieces of legislation is through the power of the commission to employ rights advisers. Those rights advisers are employees of the commission who implement the three pieces of legislation.

Briefly, the ministry is currently consulting with community groups, holding focus sessions to look at future directions in advocacy—I'm not going to speak to

the rights advice pieces of the legislation—to look at how the community can become more involved, how services that exist can be better coordinated and strategies for dealing with advocacy and situations of abuse and neglect. That's it.

**The Chair:** Are there any other individuals representing the ministry who will be making a presentation?

**Ms Carr:** Not from the Ministry of Citizenship.

**The Chair:** So we have lots of time available for questions.

**Mr Bernard Grandmaître (Ottawa East):** Did you have an opportunity to work on Bill 79?

**Ms Carr:** Bill 74? You mean the original Advocacy Act?

**Mr Grandmaître:** Bill 74, yes.

**Ms Carr:** No, sir.

**Mr Grandmaître:** So you're brand-new with the ministry, or what?

**Ms Carr:** No, my portfolio started in June, but the ministry did not craft Bill 74, as I understand it.

**1440**

**Mr Grandmaître:** So you didn't have a chance to work on the previous bill?

**Ms Carr:** Not this one, no.

**Mr Grandmaître:** Then I'm going to ask you a difficult question that may be a little touchy. The minister was quoted as saying that it was an \$18-million bureaucracy. What are your thoughts on this \$18-million bureaucracy?

**Ms Carr:** My thoughts on it? Do you want a status report on the—

**Mr Tilson:** Surely that's not an appropriate question. It's more appropriately asked of the minister.

**Mr Grandmaître:** Why not?

**Mr Tilson:** These people are instructed to prepare a submission—

**Mr Grandmaître:** I think the lady is capable of answering for herself. If she doesn't want to, she will say no.

**Mr Tilson:** But surely the next question you're going to ask is what her political affiliation is. I mean, how far are you going to go?

**Mr Grandmaître:** She'll say no, period. If she doesn't want to answer, she'll say no.

**Mr Tilson:** I say the question is out of order, Mr Chairman.

**Mr Grandmaître:** Are you her guardian? When were you appointed?

**Mr Tilson:** I'm simply saying that asking for her political thoughts is out of order.

**Mr Grandmaître:** I'm not asking for her political thoughts.

**Mr Marchese:** Mr Chairman, can I say something? Where the person thinks it's a political question, she can simply say that is the case and move on.

**The Chair:** Yes, she can. She can simply say no. That's the simple answer.

**Mr Grandmaître:** Is it too political for you?

**Ms Carr:** Yes, sir.

**The Chair:** We have an honest witness.

**Mr Grandmaître:** Thank you. Now I want to talk to you about consultation. Mrs Caplan did ask the minister



to provide us with the list of groups that were consulted and you've just mentioned that this consultation is still ongoing, right?

**Ms Carr:** Yes.

**Mr Grandmaître:** You did say this? Okay. Can you tell us what kind of consultation you have had on this section of the bill?

**Ms Carr:** On the advocacy?

**Mr Grandmaître:** Yes, on the advocacy.

**Ms Carr:** There have been, I believe, 10 focus group sessions. A consultant was hired so there have been focus group sessions. There have also been individual interviews by the consultant with experts in the field. There is an interministerial group which is bringing forward various other pieces of legislation and program expertise and, to some extent, this process as well is part of the consultation exercise.

**Mr Grandmaître:** And it's still ongoing?

**Ms Carr:** I believe that the actual focus groups have finished and the individual interviews are still going on.

**Mrs Caplan:** I appreciate particularly the last question, because I think what it tells me is that what they're working on is trying to find an approach to advocacy in the future. Is that the purpose?

**Ms Carr:** That's correct.

**Mrs Caplan:** I think that's very interesting because clearly the reason is that there's a recognized need for advocacy services within the ministry. Could you elaborate on that a little bit? I know that much of this is health legislation and the Attorney General's ministry as well, but even though your ministry didn't draft the last legislation, obviously they were committed to advocacy because of the obvious need for advocacy services. Did the ministry propose any alternative models to the minister that you know of before the decision was made to just repeal this act and start from scratch?

**Ms Carr:** I think the decision to repeal came pretty quickly. The minister was certainly open to looking at new ways—I can only speak for my minister—of looking at advocacy services that made the best use of existing government and community resources, and that's the process now. That was in her press release.

**Mrs Caplan:** And that's what's going on now. Now you're effectively starting all over to look at what would be possible as far as the development of advocacy services. Do you know if your minister has any authority to consider any amendments to this legislation that would give a foundation for protection of some advocacy services without having separate legislation? Is that something that would be possible to be considered? Or you just don't know?

**Ms Carr:** I don't know that advocacy fits in this legislation or other existing legislation.

**Mrs Caplan:** I think that's fair comment. The issue of rights advice of course was a part of advocacy, and what we heard the minister say was that the Advocacy Commission has spent most of its time on rights advice. Could you tell us where that rights advice was generated from or the need for that rights advice? Did the commission keep any data or statistics on where it was getting requests from?

**Ms Carr:** Yes. Because they report to the ministry, they would give monthly intake statistics, so between April 3, when they first started doing the rights advice, to December 31—do you want them under the different pieces of legislation? Under CTA, the Consent to Treatment Act, 1,096; under the Mental Health Act, 5,654, the bulk of them; and under the Substitute Decisions Act, 452. Those were actual rights advice intake calls.

**Mrs Caplan:** So there were over 5,000 under the Mental Health Act and under the Consent to Treatment Acts there were about 2,000?

**Ms Carr:** One thousand.

**Mrs Caplan:** And under the Substitute Decisions Act?

**Ms Carr:** Four hundred and fifty-two.

**Mrs Caplan:** The question I have is, when this legislation passes, we've got—now, these were since April, these 6,500? That's a round number, that's a fair—

**Ms Carr:** It's around 7,000.

**Mrs Caplan:** We've had 7,000 individuals, whether they are providers or family members or patients, calling the Advocacy Commission for rights advice assistance on knowing what their rights were. When this legislation passes, is there any capacity that you know—other than for in-patients in a psychiatric hospital who would receive rights advice from the psychiatric patient advocate office—is there any place else these 7,000 people could call to get rights advice?

**Ms Carr:** I probably am not the right person to speak to that. I think you'll hear from the Attorney General and the Minister of Health what the plans are for rights advice provisions.

**Mrs Caplan:** Thanks very much. Of course, that's a concern and your ministry's identified that there is a need for advocacy services, but that's separate from the need for rights advice. People won't even know where to call to find out rights advice. There's a need for that advice, whether it's families or providers or individuals.

Do you have a breakdown from the Advocacy Commission as to where those calls are generated from, how many came from families or individuals?

**Ms Carr:** Do you mean who made the calls?

**Mrs Caplan:** Who made the calls.

**Ms Carr:** I don't have that.

**Mrs Caplan:** Is there any way you could get us that information? Would that be something you could ask about?

**Ms Carr:** I can find out. I don't know whether they tracked it from that perspective. The question would be, who generates the rights advice calls to the commission? I'd have to go back and find out.

**Mrs Caplan:** That would be helpful.

**Mr Marchese:** Ms Carr, you came into this employ, whatever you're doing, in June?

**Ms Carr:** I became involved with the advocacy work.

**Mr Marchese:** In June?

**Ms Carr:** Yes.

**Mr Marchese:** As of this very past June?

**Ms Carr:** Yes.

**Mr Marchese:** Who was involved in this field prior to you?

**Ms Carr:** There was an advocacy project team that worked on the policy work. It wasn't at arm's length but it was separate from inside the ministry's policy field.

**Mr Marchese:** I see. Where is this project team now?

**Ms Carr:** Once the legislation went through, I believe the project was finished. It was to develop the legislative work and the program work.

**Mr Marchese:** So in terms of people who might have had a great deal of experience in drafting this, you were not one of those? Is that correct?

**Ms Carr:** That's correct.

**Mr Marchese:** So we don't really have someone in the ministry who would have been able to defend what we did or what was done before, other than whatever you've gathered so far, as of June?

**Ms Carr:** That's correct. My understanding was that it was drafted outside the ministry.

**Mr Marchese:** Oh, I see.

Can you explain to us a bit about what the commission was doing in terms of rights advice as it relates to systemic kinds of changes and systemic rights advice?

**Ms Carr:** You mean advocacy, systemic advocacy?

**Mr Marchese:** You talked about four kinds of advice or advocacy and you listed that as being one of them.

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**Ms Carr:** They started off with rights advice because that was mandatory under the other legislation. In terms of systemic advocacy, they had set up a regional network and were working with the community to help the community ready itself for the next phase of advocacy. So they had been encouraging community groups to work together to share information, to share training, for example, and to work together basically at the community level. That was sort of the first phase.

**Mr Marchese:** To deal with systemic problems that there might be in institutions or wherever vulnerable people are.

**Ms Carr:** That's correct.

**Mr Marchese:** So with the repeal of this act, this will disappear, obviously. Is that correct?

**Ms Carr:** The commission part of it will. The momentum might be there in the community to continue it.

**Mr Marchese:** Is it your sense or belief that somehow that will be picked up by whatever is left over or whatever the ministry can do to pick up the work of the commission was doing with respect to systemic—

**Ms Carr:** I don't know how to answer it, because there are many groups in the community that are involved in systemic advocacy. Whether they will continue to work together or whether there will be initiatives to encourage that, I don't know.

**Mr Marchese:** Are you familiar with the kinds of expenditures that the commission has been working under since it's been operating?

**Ms Carr:** Yes.

**Mr Marchese:** Can you give us a breakdown of what the commission was originally given, what the cuts meant in July and what they've been working with since July?

**Ms Carr:** They were originally allocated \$18 million.

**Mr Marchese:** Not \$30 million and not \$100 million? The original allocation was \$18 million. Is that correct?

**Ms Carr:** That's correct. In July, there was an in-year adjustment and then a second adjustment, and the remaining was \$7 million.

**Mr Marchese:** So they cut \$11 million?

**Ms Carr:** Yes.

**Mr Marchese:** In July there was an \$11-million cut.

**Ms Carr:** In July and I believe again in October.

**Mr Marchese:** So they were operating with about \$7 million.

**Ms Carr:** They have, as at January 31, spent \$5.1 million.

**Mr Marchese:** So if we wait another couple of months, it will disappear essentially.

**Ms Carr:** That's correct.

**Mr Marchese:** So we don't need to even wait for the repeal. Before this act is introduced, this commission is likely to disappear.

**Ms Carr:** No, it can't disappear until it's repealed, and there would be nobody to do rights advice. I believe there's enough of a budget to take it to repeal.

**Mrs Boyd:** These consultations that you've been having since the decision to repeal the act was made, are you generally finding in the course of those consultations that there is real concern about the lack of the Advocacy Commission, the lack of arm's-length rights advice?

**Ms Carr:** I think I find that a political question. I think you will find many of the people who presented or who attended our focus groups will be presenting at these hearings. I'd rather they speak for themselves on that than for me to generalize.

**Mrs Boyd:** I find that rather odd. If you're having focus groups in order to focus your attention on policy-making, surely you're aware of the results of those focus groups. I wasn't trying to be political at all. I'm just asking, what did you find out from those focus groups?

**Ms Carr:** There's both concern and support for repeal of the act.

**Mrs Boyd:** I see.

**Ms Carr:** Not among the same people.

**Mrs Boyd:** Can you give us some idea of what the major concerns are that are being expressed?

**Ms Carr:** In general terms, the concerns that you will no doubt hear about are concerns around community resources, resources to the community-based services, mandatory rights advice. I'd say those are the three main areas of concern.

**Mrs Boyd:** Then is it my impression that the ministry is waiting to come forward with any policy suggestions around the provision of rights advice and advocacy until after the hearings of this committee are completed?

**Ms Carr:** We're not coming forward with rights advice, but in terms of advocacy there are provisional scenarios, provisional options that formed part of the minister's consideration and, in general terms, provided a framework for the focus groups to see what was important to them.

**Mrs Boyd:** But I think my question really was, would you be able to present those options to the committee in the course of our hearings so that we have some idea of what it is the minister is considering as possible options to replace the Advocacy Commission? I think it might allay a lot of the anxiety that's been expressed if we had some idea of what kinds of options the ministry is considering.

**Ms Carr:** I don't know that I can make that determination. I can ask.



**Mrs Boyd:** That would be helpful.

**Mr Clement:** I think Ms Carr has done a good job in correcting the record, but I just wanted to make sure that we all had the same information with respect to expenditures. I believe Mr Johnson has a question, but I wanted to again put on the record, as a result of the Minister of Citizenship, Culture and Recreation's statement, that the original budget for the Advocacy Commission was \$17,781,600. Due to in-year adjustments, that pricetag was reduced by a total of \$10,628,900, leaving a revised budget of \$7,152,700. Actual expenditures as of January 31, 1996, were \$5,151,490. There was some suggestion that the commission had spent \$18 million. That was in fact their budget allocation and they actually have in their budget allocation \$5.1 million. That still works out to \$500,000 a month, though, which is the number we have been operating under. I wanted to revise the record.

**Mr Ron Johnson (Brantford):** Ms Carr, just to use some of the numbers and some of the information that you were giving us earlier, you indicated that at the present time the Advocacy Commission is really spending most of its resources in terms of rights advice at this point, and some referral stuff. Is that correct?

**Ms Carr:** That's correct.

**Mr Ron Johnson:** I guess I'm looking at the approximately 7,000 cases in terms of where they've given the rights advice. Do you have any indication about how long one would go through consultation or rights advice from an advocate?

**Ms Carr:** How much time it takes?

**Mr Ron Johnson:** Yes, how long would that take per case, on an average? Is it a few hours, a couple days?

**Ms Jutta Auksi:** My name is Jutta Auksi. I'm with the Ministry of Health. The actual rights information is a relatively small amount of information. Someone I think said that the actual information could probably fit into five minutes. No one is saying that it would only take that long, because by definition in the cases where rights advice is required, the person is either somewhat or very incapable mentally, or maybe in a very agitated state because they're civilly committed, various things, so that it would actually take longer because of the nature of that communication.

But it certainly isn't something that's a very lengthy thing. It's a relatively short amount of information, simply telling the person that whatever particular legal status of theirs is at issue, they have a right to have that reviewed at the review board. Only if they want, they can find out about what is involved in going to the review board and how they can apply, assistance with applying if they want and getting perhaps assistance with making a legal aid application or getting a lawyer in some other way, bearing in mind that very few people actually do opt to go for a review. So it would only be in a limited number of cases that there would be that expanded amount of information.

**Mr Ron Johnson:** I just wanted to make a couple of brief comments, and another question. I find it interesting, and it's unfortunate that you often have to focus on the bottom line when you're looking at organizations like the Advocacy Commission, but I see a budget or expenditures so far of over \$5 million, and really what we've

done with that \$5 million is listened and given rights advice about 7,000 times. That's around \$750 to \$1,000 per case. I think that in the interest of operating efficiently and seeing what we can do in looking at alternatives, it's important that this committee bear in mind that although on one hand we have to make sure that certain advocacy services are made available, it's very important to explore some of the alternatives, because this is clearly a commission, in my view, that is operating, in terms of expenditures, excessively for the taxpayers.

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**Mr Tilson:** I'd like you to make some comments about the advocates. The rights advice process, you say, started right away, shortly after the bill became law. I think you mentioned April 3. Can you tell us, how does one become an advocate? What is the training?

**Ms Carr:** For advocates?

**Mr Tilson:** Yes.

**Ms Carr:** As opposed to rights advisers?

**Mr Tilson:** Yes, as opposed to rights advisers.

**Ms Carr:** There's provision in the act for training in standards, but they hadn't begun to train advocates yet.

**Mr Tilson:** I just can't believe you started on April 3. How could there possibly be any training? I'm not saying you, but the commission.

**Ms Carr:** The rights advisers who were providing the mandatory rights advice were trained by the commission.

**Mr Tilson:** Obviously before the bill became law.

**Ms Carr:** We already had rights advisers through the Psychiatric Patient Advocate Office who were already doing rights advice. I think they were doing some of the training as well.

**Mr Tilson:** So how many advocates are there today?

**Ms Carr:** Rights advisers?

**Mr Tilson:** Yes.

**Ms Carr:** Or advocates? Rights? I don't know the answer to that. I can find out.

**Mr Tilson:** Does anyone else know that?

**Ms Carr:** You mean including PPAO? I think the commission hired about 46.

**Mr Tilson:** Forty-six. I'm just trying to justify this spending of \$500,000 a month. I just wonder where the money goes.

**Ms Carr:** The rights advisers have to meet in person. Often there's a great deal of travel involved. Not every community has rights advisers available to them, so there are those travel expenses. Not all the costs that they spend per month are on rights advisers. They do operate an information and referral telephone line, they do the community development work and they have overhead.

**Mr Tilson:** I'll say. Can you tell us, and there may be a privacy problem here, what the pay structure is of advocates and advisers?

**Ms Carr:** The salary ranges?

**Mr Tilson:** Yes.

**Ms Carr:** We could probably provide that for you. I don't have it with me.

**Mr Tilson:** If you could get that, I'd like to know that.

You mentioned non-instructional advocacy. Can you explain that?

**Ms Carr:** Non-instructed advocacy, which they were not doing because they were not—

**Mr Tilson:** Yes.

**Ms Carr:** That is a situation in which the individual cannot instruct an advocate. So either the advocate knows from prior conversation or some other way what the individual's wishes are, but right at that time they are not instructing their advocate.

**The Chair:** Thank you, Ms Carr.

#### MINISTRY OF HEALTH

**The Chair:** We now will have the Ministry of Health. Ms Perun is counsel for legal services branch and is accompanied. Perhaps you could identify yourself, sir.

**Mr Gilbert Sharpe:** Gilbert Sharpe. I'm the director of legal services in the Ministry of Health.

**Ms Auksi:** I'm Juta Auksi. I'm senior consultant in the legislation policy unit at the Ministry of Health.

**The Chair:** Thank you. We're following our rotation. Mrs Caplan.

*Interjections.*

**The Chair:** Oh, I'm sorry. Yes, Mr Tilson, you're quite right. Ms Perun, you have the floor.

**Ms Halyna Perun:** Thank you, Mr Chair. Mr Sharpe will start the presentation.

**Mr Sharpe:** Having been around the Ministry of Health forever, I suggested that I perhaps might put the issues in a bit of perspective historically, since I seem to be the resident historian. If the committee wishes, perhaps I could do a bit of that for a few minutes.

I'm sure everyone's well aware of issues relating to consent to treatment, the common-law right of us all to refuse treatment if we're mentally capable and the need to have information given to us that would let us make choices and all of those things.

The problem of course to common law is that there was no means of getting substitute consent to care of any kind unless there's legislation that provides a substitute with that role or unless there's a guardian, which in most cases doesn't exist. For example, historically, if you had an elderly aunt who you wanted to assist by getting into a nursing home and consenting to treatment there, you as a family member would not have the legal right to make either decision for this person, even though they might not be mentally capable. Practically, those decisions have been made, historically, even though there has been no legal protection for the facility or its physicians and other care providers.

When I first joined the ministry in 1975, one of the first tasks I was asked to look at was a cabinet submission dealing with treatment. At that time it split ordinary and extraordinary treatment but was an attempt to codify the common law and provide some consistent rules for consent and substitute consent.

Some of you may remember, in 1977 the then official guardian of the province, Lloyd Perry, made public the fact that there had been about 400 contraceptive sterilizations performed in the province on persons under 16. The government of the day was very concerned about a number of issues relating to that, including who was providing consent to those non-therapeutic interventions for these young people, and the government established an interministry committee of the ministries of Health,

Community and Social Services and the Attorney General. The official guardian and public trustee of the day were also on the committee. The committee looked at issue relating to sterilization but also was asked to examine matters generally of consent to treatment, and in 1979 the Ministry of Health released a report called Options on Medical Consent that recommended comprehensive consent legislation.

About the same time, the Mental Health Act amendments were moving through the Legislature and it was decided to try to put some provisions in that bill relating to consent to treatment. There were some provisions added at that time that have since been amended, and of course ultimately replaced with the consent legislation last year, but that statute as well attempted to deal with issues of substitute consent, respect for autonomy in wishes and other matters.

In 1980, this interministry committee's mandate was expanded again to look at matters relating to protection for elderly people, the elder abuse issue, and also issues surrounding the Mental Incompetency Act, the great difficulties in using that statute, the delays and costs and standards of proof and so on, matters relating to guardianship. A couple of years after that the so-called Fram committee was set up to provide a forum for community input around the table and for broader discussions, primarily focusing on the guardianship aspects of the legislation. We all know that during that process, Father Sean O'Sullivan was asked to look at matters relating to advocacy, the Manson report on advocacy in psych hospitals was developed, and other related things that happened through the 1980s.

In 1987 the Mental Health Act was amended, looking at questions of competency to consent to treatment, among other things, issues of the ability of a provider to decide that any of us are not capable of making decisions about treatment and simply on that say-so going to someone else without any review mechanism or without any opportunity to challenge. This of course was sharply contrasted with the old Mental Incompetency Act, where in order to remove our assets there were formal proceedings with criminal standards of proof and all kinds of notice provisions and due process.

So in the 1987 amendments to the Mental Health Act, the review board, which has existed since the 1960s, when the first Mental Health Act was established, was given the authority not just to review matters of commitment—involuntary hospitalization—but also questions where patients felt that they had been improperly declared incapable of consenting to psychiatric treatment. This was in 1987.

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In fact, many of the changes to the Mental Health Act foreshadowed somewhat the ultimate changes in the consent legislation: the fact that autonomy should be respected; the notion that one's wishes, if clear, should carry rather than best interests, which would be a fall-back; the ability to select the substitute rather than just having a list of people who would be triggered, which was the traditional approach used in the Mental Health Act since 1978—better to have, where possible, one select the person they feel closest to to make decisions;



and, as I said, the appeal to a tribunal. Many of these changes appeared first in the Mental Health Act and ultimately in the consent legislation.

As we were moving through the 1980s, other statutes from time to time would have consent aspects and would be amended. For example, the Health Protection and Promotion Act in 1986 amended the old Public Health Act, and a provision was added requiring informed consent to immunizations. That provision was not brought into effect immediately because of concerns expressed by physicians in terms of nursing home problems and getting substitute consents where, as I say, the law did not provide a mechanism to do that. There was no comprehensive consent statute.

In 1990, a consultation paper was released proposing omnibus comprehensive consent legislation, and about this time the Weisstub report on mental competency was also released. Of course, then in 1991-92 various drafts of the consent legislation were put forward, and of course they became law in April.

That's a very brief overview of a very long history, for me, and a very interesting one. I must say that many of the issues that you'll be looking at over the next few weeks, again, there is quite a bit of history to. We, of course, would be pleased to assist in any way in expanding on them.

**Ms Perun:** My task here is to take you through the critical parts of the Health Care Consent Act. So if I may begin by referring you to page 2 of the legislation, the Health Care Consent Act is referred to in part II. Essentially, there are just two subsections, one that says that the Health Care Consent Act as set out in schedule A is "enacted and comes into force on the day this section comes into force," and then subsection 2(2), repeal of the Consent to Treatment Act, also has effect on the day the section takes effect.

The substance of the legislation, however, is found in the schedule to the entire bill, and that begins at page 60. So if we could take a look at page 60, and I'd like to go through the table of contents with you just very briefly, you will note that the new Health Care Consent Act preserves most of the fundamental principles of the old Consent to Treatment Act with respect to treatment and expands those principles for admission to care facilities, which is in part III, and provides a substitute decision-making scheme for personal assistance plans, which is found in part IV.

Some of the old definitions that were found in the Consent to Treatment Act have been reorganized. They apply to all parts, so therefore they now appear in part I, the general provisions dealing with definitions and interpretation.

So part I, if I may take you through that very briefly, a new section, one that does not appear in the Consent to Treatment Act, is the purpose section of the act. Essentially, it talks about what the goals of the legislation are, and that is provided in section 1.

Part II continues to codify the law of informed consent to treatment. That begins on page 68. I will refer to the other definitions from time to time as they come up in the context of the discussions around the parts themselves. Part II provides uniform consent rules wherever

treatment is provided, and it applies to most of the regulated health professions. Who is covered by the legislation is defined by the phrase "health practitioner." "Health practitioner" is defined at the beginning of the legislation and essentially is all of the regulated health professions except for—who is not covered by part II are opticians, pharmacists and dental technologists. Part II does not apply to them, but for the other regulated health professions this act applies as well as to the naturopaths.

There continues to be a very broad definition of what treatment is. Again, I'll refer you to the definitions section. "Treatment" is defined on page 66 of the definitions. The act applies to "anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment or plan of treatment, but does not include," the following things.

This is similar to what exists currently in the Consent to Treatment Act, except that in the new act some of the items you see in some fashion in clauses (a) through (g) appear in a regulation under the Consent to Treatment Act and now they have been brought up into the legislation.

The kinds of things that this act does not apply to are assessments done for the purposes of deciding capacity, as is set out in clause (a); "(b) the assessment or examination of a person to determine the general nature of the person's condition"; "(c) the taking of a person's health history"; "(d) the communication of an assessment or diagnosis"; "(e) the admission of a person to a hospital or other facility"—that's there for clarification; "(f) a personal assistance service," and that is then itself defined. There's a definition of what a personal assistance service is set out on page 65 as a definition. Lastly, what the act does not apply to is "(g) a treatment that in the circumstances poses little or no risk of harm to the person."

The principles of consent are set out in sections 9, 10, 11 and 12 of the legislation, the main principle being that "A health practitioner who proposes a treatment for a person shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless," the person has consented and, if the person is not capable, someone else has consented in accordance with the legislation. This is not new. This is the language from the Consent to Treatment Act.

The elements of consent are set out in section 10, and again this is a codification of what the common law provided and is continued from the Consent to Treatment Act. The consent must relate to the treatment, it must be informed, it must be given voluntarily and it must not be obtained through misrepresentation or fraud.

What is an informed consent is set out in subsection 10(2), and the language here has been somewhat streamlined. The language is similar to what is currently there in the Consent to Treatment Act, but the matters referred to as to the primary aspect of an informed consent have been itemized in subsection 10(3), numbers 1 through 6. So for clarity, it's easier to read this subsection.

But also the primary difference between the Consent to Treatment Act and this new Health Care Consent Act is that there is no longer an obligation on the practitioner to



disclose every possible risk and benefit of every alternative course of action. That was the old language of the Consent to Treatment Act. Here it's simply that disclosure has to be made as to the alternative courses of action.

Subsection 10(4) continues the notion that consent to treatment may be expressed or implied.

Completely new is section 11, which provides that a health practitioner is entitled to presume that consent to a treatment includes a consent to a variation or an adjustment in the treatment, provided that the risks and benefits are the same. So if we're talking about an antibiotic for an ear infection, if one doesn't work, the practitioner can use a different one without having to go back to the person or the substitute for a fresh consent.

Secondly, in clause (b) what is new is that the health practitioner is also entitled to presume that consent to a treatment includes consent to the continuation of the same treatment in a different setting. So if a person is moved from one floor to the other, that person brings medications with him or her, and there is a presumption that the treatment can continue until such time as there is a need for a new consent.

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In section 12, and I should mention actually, in the current Consent to Treatment Act, there is a definition of treatment which includes a course of treatment or a plan of treatment, but there is no legislative definition of what those words mean. The new Health Care Consent Act actually defines what a plan of treatment is and what a course of treatment is. That is again set out in the definitions section.

"Course of treatment" is defined on page 64 and "plan of treatment" is defined at the bottom of page 65 and at the top of page 66. The definitions come essentially from the practice that was developed around the Consent to Treatment Act. A plan of treatment, then, means a plan that is developed by one or more health practitioners, deals with one or more of the health problems that a person has or is likely to have, given the person's current health condition, and provides for the administration to the person of various treatments or courses of treatments. So essentially one can manage and obtain a consent to the entire plan of treatment at the outset.

Further direction is then provided in section 12 around how a plan of treatment is to be proposed. It provides that one health practitioner may propose the plan of treatment on behalf of all of those involved in the treatment team, can decide about capacity and ensure that consent is obtained in accordance with the act. This section puts the responsibility on one practitioner to manage the obtaining of the consent.

Essentially how the act works is the same way as the Consent to Treatment Act works. If a person is found capable, the health practitioner turns to the person for consent. The act therefore addresses what is capacity and then what happens when a person becomes incapable.

First of all, the definition of "capacity" is brought right up in part I, because that definition is applicable to part II, part III and part IV. So the definition of "capacity" is set out in section 3 on page 67. It continues to be a twofold test. "Capacity" with respect to treatment or admission or a personal assistance plan is the ability to

understand the information that is relevant to a decision and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of a decision. The act goes on to clarify that a person is presumed to be capable with respect to these matters unless it's not reasonable to presume so.

These are new provisions. They are not in the current Consent to Treatment Act itself. They appear in the regulation under the Consent to Treatment Act and they're brought from the common law into the statute. They are found in subsections 3(2) and (3). There continues to be no age of consent in the legislation. Section 3 simply codifies the presumption of capacity and sets a definition of what capacity is.

If a person is incapable, certain things follow. The person has certain rights of review of the finding of incapacity and the health practitioner can turn to a list of substitute deciders to obtain a decision around the treatment. The list of substitute decision-makers is located in section 18 of the legislation. That's at the bottom of page 72, top of page 73.

What the act no longer provides is any direction in the legislation to the health practitioner to inform the person of their rights after a finding—

**Mrs Caplan:** Could you repeat that?

**Ms Perun:** What the act does not provide any longer is a requirement in the legislation that the health practitioner inform the person of a finding of incapacity and no longer provides this requirement that the health practitioner must give a notice of rights in certain instances. The current Consent to Treatment Act does that in section 9 of the legislation. It deals with psychiatric treatment and people who have been found incapable of treatment in a psychiatric facility and then it provides other rules for where a person is found incapable of treatment; that is a controlled act, which is a defined term in the Regulated Health Professions Act. This act removes that.

I didn't really want to deal at this juncture with the consequential amendments, but I think it is useful to point out to the committee that there are certain amendments that have been done to other legislation under this bill that do preserve rights advice, and so I would like to point that out.

The Mental Health Act is being consequentially amended to provide the ability to prescribe who rights advisers are going to be, who will be providing rights advice in psychiatric facilities, and that is located on pages 52 and 53.

Actually if I could just start a little bit earlier, the definition of a rights adviser under the Mental Health Act is found on page 47. It means "a person, or a member of a category of persons, designated by a psychiatric facility or by the minister to perform the functions of a rights adviser under this act in the psychiatric facility."

Then, by regulation, which is set out on pages 52 and 53, there is a reg-making power to define who these rights advisers are going to be, to set their qualifications and requirements; then further, in clause (j), to prescribe and govern the obligations of practitioners, rights advisers, psych facilities and the like around providing information to persons who have been admitted to a psych facility as patients and who are incapable with



respect to treatment of a mental disorder. So those are amendments that are done to the Mental Health Act.

But the current Mental Health Act requires in the legislation that for certain things a rights adviser be notified. For example, where someone has been involuntarily committed there is a requirement to notify a rights adviser; or where a child is informally admitted between the ages of 12 and 15, there's a requirement right in the act to provide a meeting with the rights adviser.

The other amendments that have been done consequentially as well under the three long-term-care statutes, that is, the Charitable Institutions Act, the Nursing Homes Act and the Homes for the Aged and Rest Homes Act, there is a regulation-making power to prescribe the kinds of information that is needed to be provided to an incapable person prior to admission to a long-term-care facility. Those are set out on pages 36, 56 and 41.

How is a consent or refusal of treatment to be obtained on behalf of an incapable person from a substitute decision-maker? The Health Care Consent Act, like the Consent to Treatment Act, enshrines the fundamental principle that a person can express a wish in any form while capable and when that person becomes incapable, that wish must be respected in deciding about making decisions around treatment. Now if a person does not know of a wish, the act continues to provide a best interests scheme, and those provisions are set out in section 19 of the legislation.

The new features of section 19, the wishes—best interests perspective, are that guidance is given in the legislation now with respect to deciding around stabilizing the person's condition. That is new. That is set out in clause (c), on page 75, and there's one little (i), (ii) and (iii), an analysis of the deterioration of the person's condition.

A few new features around substitute decision-makers: Just to highlight, there is now a definition of who a relative is. That was not present in the Consent to Treatment Act. "Two persons are relatives for the purpose of this section if they are related by blood, marriage or adoption." The definition of spouse is clarified. The ranking of the custodial parent versus the access parent has been clarified as well.

There no longer is a prohibition on substitutes to consent to the use of electric shock as aversive conditioning. That is set out in the current act, section 14, and there is no mention in this act to that.

#### 1530

There continues to be an emergency exception to the requirement of consent. The emergency exceptions are located at section 23 and beyond. There are some minor wording amendments, but what is in fact totally new is subsection 23(3), on page 77. It essentially deals with the capable emergency, where a person may be very much in need of treatment but it's an emergency; there is no ability to communicate with the person; all reasonable steps have been taken; delay required to find such a means would prolong the suffering of the person; and there's no reason to believe the person does not want the treatment. That is something new.

With respect to protections from liability, again they're continued from the Consent to Treatment Act. The

protection-from-liability provisions have been extended to address the withholding or withdrawal of treatment. That is set out in subsection 27(3). Further, the protections from liability address the admission decisions made as a result of the fact that someone has been found incapable and a substitute is consenting to the admission as well. That has been added as a clarification to the protection-from-liability provisions.

As indicated earlier, an incapable person continues to have certain rights of review. That person may apply to the board. It's now called the Consent and Capacity Board. Under the Consent to Treatment Act, it is the Consent and Capacity Review Board. The name change is to clarify the confusion with another board that has the same CCRB lettering.

The difference is that the Consent to Treatment Act basically says: "Wait. Do not treat until a meeting with a rights adviser occurs where that is requested." That is no longer there, but the act continues to say that the health practitioner shall not begin the treatment, the treatment shall not be commenced, if the person indicates an intent to appeal to the board, but it's also just the first intention. Subsequent intentions do not trigger that: "Wait. Do not treat."

In addition, with the new provision under the Health Care Consent Act now, there is no longer a prohibition not to treat within the seven-day waiting period. Under the current Consent to Treatment Act, the health practitioner must wait seven days even if the review board confirms the finding of incapacity and even if a person does not intend to appeal. It has been clarified that the treatment can commence if the person does not intend to appeal, but is preserved for those who wish to appeal.

The various other types of applications in existence under the Consent to Treatment Act continue under the Health Care Consent Act; for example, an application by the substitute for directions if wishes are not clear about treatment and the like. What is new is section 35, set out on page 85 of the legislation. Section 35 provides an ability to the health practitioner to make an application to the board where a substitute decider, in the opinion of the health practitioner, is not abiding by either prior wishes expressed while capable or is not abiding by the "best interests" criterion if such wishes are not known.

The other two parts contained in the Health Care Consent Act were not part of the Consent to Treatment Act. That is part III, dealing with admissions to care facilities. "Care facility" is defined in part I as the three long-term-care type of facilities we have under the three long-term-care statutes: nursing homes, homes for the aged. The definition itself is found on page 64. Part IV deals with personal assistance plans, personal assistance services, provided in these type of long-term-care facilities and others that may be added by regulation.

Generally, not to belabour going through all these provisions, they mirror the Consent to Treatment Act wherever possible. The language change reflects the different purpose of the parts, that we're dealing with admission as opposed to treatment decisions, but wherever possible the same flow follows. For example, first of all the requirement is set out in section 38, in part III, at page 86, "If a person's consent to his or her admission to



a care facility is required by law and the person is found by an evaluator to be incapable with respect to the admission," who can consent to the person's admission is then further set out. That is basically in section 39, that it's section 18, the substitute decider as listed in part II, with necessary modifications.

Who is an evaluator? An evaluator is the person described in the definition up front in part I, at page 64. It means "in the circumstances prescribed by the regulations" a person who is an audiologist, a speech-language pathologist, a nurse, an occupational therapist, psychologist, physiotherapist, a physician—those types of people who work with issues around admission to long-term-care facilities and would be in a position to do evaluations of incapacity.

That is how part III works. Again the premise is where consent to admission is required by law, and that wording links it back to the three long-term-care facility statutes that require consent for the purposes of admission to a long-term-care facility. And again the admission decision has to be made in accordance with wishes, if known; if not known, the "best interests" criterion. The incapable individual has rights of review similar to the treatment part; if the person asks for a review of the finding of incapacity, admission cannot occur until such time as the incapacity issues have been resolved.

What flows from having a substitute decision-making theme in this legislation is that there's an easier mechanism to turn to an appropriate family member for substitute consent, and ultimately, if a substitute is not around, the public guardian and trustee, the substitute decider of last resort, has a responsibility to decide about the admission.

Protections from liability flow from that. They are similar to the types of protections from liability that exist in part II for health practitioners.

Part IV deals with personal assistance plans. Very briefly, part IV applies to personal assistance plans in care facilities. What is a personal assistance plan? That is set out in the definition section—"personal assistance plan" means a plan developed by a care facility that describes one or more personal assistance services—on page 65, and the personal assistance service is then also defined.

Part IV does not say when a consent is required or when it is not required. It merely provides that where a resident is found by an evaluator to be incapable, a decision may be made on the resident's behalf by a substitute decider. The word "resident" is also defined in the definition section in part I.

That person, if they have been found incapable by the evaluator, has a right of review of the finding of incapacity. That person may ask the board to appoint a representative to make decisions on his or her behalf. Also, a substitute can seek directions from the board about wishes that were expressed at an earlier time.

1540

Part V deals with the Consent and Capacity Review Board. The provisions around the board are similar to those that exist now under the Consent to Treatment Act, with a couple of new features. First of all, there is no longer a requirement that for a case involving capacity,

one member of the panel shall be a person with expertise in evaluating capacity. Second, the chair may assign a member to sit alone to deal with applications. That is set out in subsection 71(2), on page 102. There are certain qualifications that member must have before being able to sit as a one-member panel, and they are set out in clauses (a) through (d).

There are certain requirements to preserve a three- or five-member panel. They are located in the Mental Health Act still. The Mental Health Act provides that for involuntary admission reviews, for example, there always be a three- or five-member panel, and the same is preserved for reviews of informal admissions of children between the ages of 12 and 15. The three- or five-member panel is preserved there as well.

Part VI deals with miscellaneous provisions, including some offence provisions, in that, for example, it is an offence to knowingly contravene wishes expressed by a capable person. That is set out in section 82.

The remaining transitional provisions are quite detailed, very technical in nature. Essentially they are there, on page 108 and following, to ensure that there is a flow between the old rules and the new rules without any gaps. That's the intent of these very technical sections of the legislation.

Finally, a number of consequential amendments have been made to other acts. Some are very technical and mean nothing more than simply that the term "Consent to Treatment Act" has been replaced with "Health Care Consent Act." For example, you will note under the amendments to the Child and Family Services Act or the Children's Law Reform Act, these were amended when the Consent to Treatment Act was proclaimed in force, came into effect at the same time, and the consequential amendments just tidy up the language.

Generally, I think I've provided a comprehensive overview. There are other features of the consequential amendments that I could go through if you wish.

**The Chair:** Is that the complete presentation from the Ministry of Health?

**Ms Perun:** Yes.

**The Chair:** Mrs Caplan, starting on questions.

**Mrs Caplan:** How much time do I have?

**The Chair:** We have until 4:20, approximately a half-hour, so it's 10 minutes each, per caucus.

**Mrs Caplan:** Oh, not a half-hour for me?

**The Chair:** Sorry, Ms Caplan, not today.

**Mrs Caplan:** There are a lot of questions.

Thank you, Halyna and Gilbert and Jutta. Could you provide a summary of every place in the legislation where there is a right an individual has to make an application or appeal to the board? In every case, I'd like to know how they would know about that right.

Is there in this act any obligation on anyone to tell someone when they're incapable that they have those rights? For example, the Mental Health Act has a provision that where someone is deemed incapable under that act, there's an obligation to actually give them the forms for appeal. Is there a similar provision in this legislation?

**Ms Perun:** There isn't. Under the Health Care Consent Act, references to legislative requirements of what a health practitioner must do or must not do vis-à-vis after



a determination of incapacity have been removed. But certainly we can go through and point out the kinds of applications in existence, the kind of applications a person may be able to make to the board. And yes, under the Mental Health Act the requirements to have meetings with rights advisers have been preserved right in the legislation. There are rights of review that flow from certain things happening under the Mental Health Act such as a right of review of involuntary committal; first of all, when there is a committal it triggers a meeting with a rights adviser.

**Mrs Caplan:** I think it would be helpful for the committee if we saw a list of all the places where an individual would have a right to either make an application or appeal the finding of incapacity; if we knew whether or not there was any obligation on anyone to let them know of the finding of incapacity; who would make decisions for them if they were found incapable, whether or not they were informed of that; lastly, whether or not there is other legislation such as the Mental Health Act where the obligation does exist.

It's a policy question why those provisions were left out, because frankly I don't think it's a huge obligation to say: "By the way, you've been found incapable and here are the forms. Should you wish to appeal, you have that right." I don't think you need the language of the former act, frankly, which I thought was unduly onerous in its procedures for rights advice and so forth, but at least people should know they've been found incompetent and at least the person who makes that finding—I think you call them evaluators—that evaluator, no matter who they are, should have the obligation.

That's up front and I'd like you to give us that information. I hope the government will think about amendments that would do that, because I think anyone would like to be told that they have been found incapable of making their own decision, and secondly, that they have the right to appeal and what that process is, and even be handed an application form. Certainly I would, and I tend to look at these things on the basis of, if I feel that strongly about it, perhaps others would agree, rather than just having someone else unnamed.

Now I know that if I or anyone else signs a power of attorney for substitute decision-making, that would be the substitute decision-maker, so I'm not talking about where a power of attorney exists. I want to be really clear that's not the case.

I have a couple of other questions. I agreed with the statement from both ministers who said this was to streamline and to ensure that the office of the official guardian and trustee was the last resort. I agree with that.

As I read the legislation, I really think, and I wonder if you would agree, that there is a potential when you have lumped family together into one category—I would like to know what will happen if well-meaning relatives disagree on what's in my interest? Would that not encourage an application to bring in the public trustee faster, then, if you had clearly the hierarchy of whose wishes within the family should be listened to first?

**Ms Perun:** The hierarchy has been preserved, the one where it has been sort of clumped as a child or parent has the same—

**Mrs Caplan:** Right?

**Ms Perun:** Yes—ranking. Otherwise, the brother or sister come below and then any other relative. Ultimately, yes, if you're within one category and if you cannot say outright that you don't believe anyone else who is equally ranked as you would have a problem with your deciding, and if there's actually a dispute in the ranking, then the public guardian and trustee becomes involved.

**Mrs Caplan:** Again, I'm sure we'll hear this from presenters who are going to come forward, but I would suggest to the government that you rethink the hierarchy of ranking and make it very clear, because as this reads now, I think you would encourage the public trustee who we all think—I think we all think—should be the last resort. I should talk for myself: I believe the public guardian and trustee should be the last resort.

If it's clarified as to the hierarchy to ensure that the public guardian and trustee cannot come in if parents and children disagree by making sure those categories are clear—because I agree with you, I think that if the responsibility is not clear, then you could well see applications made unnecessarily as to who should have that responsibility. I'd ask if you'd consider that and perhaps an amendment to that or some discussion following the hearings.

1550

One of the other concerns I have is with the provisions of the Mental Health Act. We know that if a person is committed in a psychiatric hospital, an independent rights adviser will continue to let that patient know of their rights, so they will have rights that others who are deemed incapable will not. That's accurate and correct, right, Halyna?

**Ms Perun:** Right.

**Mrs Caplan:** Okay. Under this new legislation, the law will now permit an administrator of a general hospital or an administrator of a nursing home or anyone where there is no substitute decision-maker appointed, where there's no family or a caregiver—that person could be, I think, in a serious potential conflict of interest if it's the hospital administrator who makes that decision. Have you considered that under Bill 19 to put that in place?

There's another provision, as you think about that, which prohibits caregivers entirely, but it seems to me that the test should be, are you going to benefit?

**Ms Perun:** Are you talking about who these rights advisers should be?

**Mrs Caplan:** Yes.

**Ms Perun:** Right. There is again the regulation-making power that will set out who these rights advisers are going to be.

**Mrs Caplan:** But don't you think that in the legislation you could assure people that a rights adviser could not be someone who would financially benefit by that position, whether that's an heir—one of the problems with the bill is you now can have a substitute decision—I know the Ministry of Attorney General was also saying—as I read it, a decision-maker where the witnesses to it are children who would be the heirs. There's no requirement for outside witnessing and therefore people could be pressured into signing a power of attorney inappropriately where their heirs and those who will benefit economically

will be doing the pressuring and the actual witnessing of the document. So there's no outside test. That's one concern I have.

The other is, who gives the rights advice? If someone's advising you who can benefit from your making one decision or another, shouldn't the law protect against that? I understand that a lot of it can be defined and fine-tuned by regulation, but it seems to me the law should offer those protections. I'd like you to think about that and tell me if I'm wrong as I've read the legislation.

The other I guess concern I have is, are there adequate safeguards in place—well, maybe this is the next one. That's under substitute decisions; I've made a point here.

The concern I have is that we've seen elder abuse in institutions, we've seen elder abuse in families, just as we have seen, unfortunately, child abuse and those sorts of things. I'm concerned that this legislation brings with it a premise, as I said earlier on, that because the majority are good and the majority of families care about old Aunt Nellie whose money they're going to inherit, and certainly wouldn't want to consent on her part to a treatment that might lead to her early demise, there are some who in fact would want to consent to a treatment or pull the plug, because those are the kinds of decisions that these people are going to be called on to make when they have a very definite financial interest. I want to know, is there anything in this legislation that protects against that? I haven't found it.

**Mr Ron Johnson:** Section 35 does that.

**Mrs Caplan:** As we move to section 35, how is that enforced? Who's got the obligation to blow the whistle?

**Ms Auksi:** The person who would be in a position to know that something was amiss—that's always a problem, no matter what legislation says—and the person who would be in a position to know in this case would be the health practitioner who is proposing the treatment. If the treatment is being refused by the substitute decision-maker and it appears that the substitute decision-maker isn't following the substitute consent requirements, then the health practitioner can apply to the review board for direction and the review board then scrutinizes that decision.

That's something that's new. Currently, under the Consent to Treatment Act there's nothing like that and so what we have said is that if someone truly has concerns—in an emergency even the Consent to Treatment Act the health practitioner can treat notwithstanding if the substitute is not complying with the substitute decision-making rules, but in a non-emergency they pretty well have to turn to the public guardian and trustee in this investigate-protective role. People seemed to think that wasn't really enough because it's just too general and doesn't necessarily provide the immediate fix.

The other thing, of course, is that anyone else can apply to the Consent and Capacity Review Board to be the substitute decision-maker.

**Mrs Caplan:** I have some concerns about that also because anyone can make that application without even notifying the person on whose behalf they're going to be making the application.

**Ms Auksi:** But the person would be a party and certainly the review board would have the responsibility to screen out any inappropriate applications.

**Mrs Caplan:** One of the other concerns—

**The Chair:** Excuse me, Mrs Caplan. Perhaps we could move on to the third party, please.

**Mrs Boyd:** These are all the kinds of issues that arise. If, for example, you had two children, so they're in the same category, one of whom was named a substitute decision-maker for personal care and one of whom had a power of attorney for property, and given the provision to agree to the care plan which we know involves cost because the personal assistance plan involves many services for which already there are fees and probably more in the future, and there is a disagreement here between the person who holds the money and the person who wants to determine the treatment, whose view takes precedence?

**Ms Perun:** Under the health care consent provision who has the authority is the person who is the personal care substitute decider.

**Mrs Boyd:** Whether or not they can guarantee there'll be money given to provide that service. You know what this is like, you consent to the treatment and the next thing you have to do is sign the paper saying you'll pay for it. Only if that doesn't happen, then what happens?

**Ms Perun:** Then you cannot provide the treatment.

**Mrs Boyd:** Right. It seems to me this is a problem. I think it's a really serious problem, quite frankly, that we need to really look at around those kinds of disputes. We very clearly know that the personal care decider doesn't have to be the same person who is the property decider. It seems to me that unless we come to some conclusion around how that is resolved, in the best interests of the person, we've got a bit of a problem.

Given that in many cases both people may be recipients or potential recipients of an estate from this person, we really have a very big conflict of interest unless we can resolve this in a way that ensures the best interests of the person. I think that is something you need to look at and it really follows along from what Mrs Caplan was asking. It may be that when the public guardian and trustee talks to us, they have a solution for that; that would be delightful.

**Ms Auksi:** I think it really is partly an issue of whether the financial power of attorney, if that person can't do anything different because the financial resources aren't there, or whether it's a matter that they're not acting properly—if they're not acting properly, perhaps people from the PGT's office might be able to address what remedies there are if a person who's managing property is not acting in the person's best interests.

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**Mrs Boyd:** The contrast might be between the cost of maintaining someone in their home, which generally speaking, given the current funding of home care, is considerably higher than institutionalizing somebody—how that decision is made. If you can't get a doctor to say, "Either one would be all right for the person," how is that decision made? It seems to me that this issue of arousing all sorts of family conflict, when that's not what's intended—and we understand that—is a potential here, and also this issue between a parent and a child.

**Mr Auksi:** You mean the parent and the adult child?

**Mrs Boyd:** Yes, the parent and the adult child of a person who becomes incapacitated. You can have a real



three-way thing there. I agree that either the hierarchy has to be made clearer or there has to be a dispute resolution mechanism that's relatively quick, that determines what's in the best interests of the person, and that may be difficult if they haven't expressed wishes.

If in the personal decision-making thing they've expressed very clear wishes about what they want for their health, then yes, it's fairly easy to say the person holding the money bag is not acting in their best interests; that's relatively easy. But if they haven't left those instructions, that's when you get into some difficulty. It seems to me we ought to resolve that as we go along.

I'm very concerned and wonder why you would've taken the provision for someone who's capable of doing the evaluation off the board. Why would you take that protective component off your board when you're putting it down to a one-person board? That person could be a lawyer who knows absolutely nothing about the capacity evaluation.

**Ms Auksi:** First of all, in the requirements for sitting as a one-member panel, that particular lawyer-member has to have experience in an adjudicating capacity, has to have been a member of the bar for 10 years, has to have had two years' experience with the board generally.

The other thing that people sometimes forget is that the board can call upon expertise. For example, if a case comes before the board that is a very difficult call about capacity, the board can require an assessment to be done and can share the findings of that with all the parties so they can comment on it. It's not as though having special expertise on the board is necessarily the only way of getting at that kind of expertise.

**Mrs Boyd:** The Mental Health Act covers only those who are in mental health institutions. Am I right?

**Ms Auksi:** Yes. The Mental Health Act governs psychiatric facilities scheduled in the regulation.

**Mrs Boyd:** As we deinstitutionalize these people, the vast majority of people with mental disorders are living among us in the community and may or may not have capacity, yet the protections in the psychiatric institutions are not there for the person who may have a very similar problem within the community. Does that make sense?

**Ms Auksi:** The main additional vulnerability that people in the psychiatric facility and institution have is that they may be subject—and many are, who are the recipients of rights advice—to involuntary admission.

**Mrs Boyd:** Many are subjected to involuntary de-admission these days. I understand what you're saying, but I'm not sure, in terms of looking after vulnerable people, that we're really doing much to do that. The rights advice issue still comes along. It may well be that in hospitals and provincially regulated, in a formal sense, facilities, the rights advice may not be as important as it is in homes for special care or the boarding home situations, where we know how vulnerable people have been and how they've been taken advantage of in terms of being overmedicated in many cases, with treatments seeming geared to keep them quiet as opposed to for their best interests. We all know the horror stories around that, so I don't need to go on with that.

One of the real concerns is that without this requirement on people running a facility to ensure that people

know their rights around appeal, they'll never appeal. Even where we have those rights in place for young offenders, for example, we often see that they aren't actually given that information. It's a big problem. Adding to that is my concern: How vulnerable, given that there's no rights advice, is all this legislation to charter challenge again and again and again? Can you tell us?

**Mr Sharpe:** Perhaps I can jump back in. The whole question around rights advice and who should get it in what circumstances is something we've heard a great deal about over the last few years. Many providers tell us, for example, that if the provider has to Mirandize their patients, it can sometimes cause great distress to the patients and their families. I know that sounds a bit patronizing.

**Mrs Boyd:** Just a bit.

**Mr Sharpe:** They give the example of Alzheimer's patients who may be quite confused and frightened and who need an elective procedure; they may be in some pain and they've waited for the bed. To then say to that person, "You're incompetent to make your own decision; therefore we're going to go to your son or daughter to make that decision for you, and by the way, you have a right to counsel and a right to appeal to a board if you're not satisfied," could create greater distress and concern. And because there's just such a worry to begin with, they may then say: "Fine. Get me my lawyer and let me go to the board." Many times they don't want that, and how do you tell? Not that that's a justification, but that's an argument that's been made. I know health care professionals will appear before the committee, and perhaps they have other experiences that might be useful.

**Mrs Boyd:** If it's an emergency or life-threatening, the provision is there to go ahead and do that, but we're talking about things that are not serious.

**Mr Sharpe:** Elective procedures. If someone needs their gall bladder out and they're in some pain but it's not an emergency situation, they're an Alzheimer's sufferer, they're confused, the family is there and willing to consent, the bed's been obtained, is it appropriate for the physician in every case where the incapacity finding is made to tell them these plethora of rights? I'm not passing judgement. I'm just suggesting that there may be cases, as physicians and others have described, that could create greater distress for the person.

The other thing is that, as Halyna described, this legislation applies to a wide range of health care professionals in a wide range of settings. If this requirement were retained, it's arguable that if you took your granny to the dentist to have her tooth filled or to have a bunion removed by a podiatrist, and she was sufficiently unclear to be unable to give an informed consent—in fact, it was your consent; you were there and you were providing the consent to the practitioner—it would then be necessary for that dentist or podiatrist to get into this series of rights before the tooth could be filled, before the bunion could be removed. There's a host of other circumstances.

That may or may not be appropriate, but again, it was described as potentially creating some serious impediments to continuity of care, particularly for certain categories of individuals.

The other thing, and I think one of the most important aspects of all of this, is that groups like the College of



Physicians and Surgeons have told us that they were aggressively going to be pursuing what they see is really their role through their patient relation committees under regulated health professions and other means to ensure that physicians understood their obligations in dealing with their patients; that it's their role to establish guidelines; that it is professional misconduct for a member not to obtain a proper consent, and the consent rules are clearly laid down in the legislation; and that they see it as a matter of peer obligation, or the professional regulatory body's obligation, to establish those parameters and guidelines and circumstances that might take into account withholding certain types of information in very distressful situations so that the professional is able to exercise some discretion and judgement while complying with the law; that it's their role and not the government's to tell them what they must do in terms of this peer review.

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**Mrs Boyd:** Do you have an indication that they would be prepared to write that into the regulations under the Registered Health Professions Act as opposed to guidelines? Other things have now been written into the regulations that met some resistance initially, not subsequent to Bill 100, for example. Do you have a sense that that would be an appropriate compromise position here?

**Mr Sharpe:** We don't, but I know a number of these colleges are appearing before the committee, and you may decide it's appropriate to put that question to them. In speaking with hospitals, the review board itself and others, they've all spoken of their intent to promulgate the rights available to patients throughout facilities and institutions. I know that the Ministry of Health has indicated that there will be attempts to communicate through brochures and booklets in different languages and posters, without necessarily having to legislate.

It seemed a bit different than guardianship. Guardianship tends to be a discrete happening, and the public guardian and trustee is going to take over an area of your life for a defined period and gives you certain information. Treatment, of course, is a continuum where there'd be variations in the kinds of treatment and the health professionals and the settings. It was considered quite onerous to expect that in each situation where a treatment is being varied, each time a different health care professional turned up, they would have to, as I say, Mirandize their patients with these plethora of rights.

Again, there were some convincing arguments made by the CPSO and other groups that they see this as a matter of professional regulation, but as the minister indicated, it's certainly a matter of listening to people from all sides who come to the committee and keeping an open mind.

**Mr Ron Johnson:** I want to reflect a moment on some of the criticisms of the legislation so far, in particular from Mrs Caplan. I guess she initially was critical of the New Democrats, saying that the initial bill was based on the fact that the health profession was all good and families were all bad, and then she criticized our government for what she called the mirror image, in that the fundamental basis of the legislation was the belief that all families were good. Although I understand the criticism, I happen to disagree with it. The reason I disagree is that I look to section 35. I believe section 35 clearly gives—

and I want some clarification on this—practitioners the ability to apply to the board for a determination of whether the substitute decision-maker complied with section 19.

What I'm getting at here is that the legislation appears to address that very concern, that in many cases you may not have substitute decision-makers who are operating in the best interests of the patient and it gives the practitioners the power to take it to the board. And that, of course, is notwithstanding the fact that if it's an emergency situation, the practitioner is bound to act anyway in the best interests of the patient.

My question, though, where I do have a bit of concern, is if a practitioner is under the belief that a substitute decision-maker is not in compliance with section 19 and decides to go the review board with that, how long is that process? What is in place to ensure that the patient's health doesn't deteriorate further while we wait for this process to go through?

**Ms Perun:** The application to the board has to occur within seven days; it's a very short time frame for the hearing, the review, and the board, after a finding, whatever the finding is, has to render reasons within a day—that kind of thing. It's a very short time frame set out in the legislation.

The act is in fact silent on what actually is to happen with the patient in the meantime. It doesn't really say either way, "You must continue treating" or "You must stop treating," basically, but the issue would be if the health practitioner is of the view that they have a legitimate consent, they would continue treating on the basis of that consent; and if they feel that they do not, then it will be an issue for them whether they should stop or continue. It would depend on the health condition of the person. The act does not direct what actually has to happen in the situation.

**Mr Ron Johnson:** During that seven-day period?

**Ms Perun:** That's right. The board would have to meet within seven days, but it may actually meet a lot earlier.

**Ms Auksi:** We meet a lot faster. Michael Bay, the chair of the board, if he knows that something needs to be decided very urgently, I think sometimes can get these things together within a day or two.

**Mrs Caplan:** Supplementary question, if I could. I agree that would work in the situation where the health practitioner made application, but if there's nothing in here, in this legislation that requires notification of a person who's been deemed incapable, how would they apply to the board if a decision has been made to treat them and they don't know that they have been found incapable? Section 35 would not help them even though they're listed here as an incapable person, would it?

**Ms Auksi:** This isn't the review of incapacity.

**Mrs Caplan:** Right, I know. The situation is this, and it's exactly—I think it's a very good point that was raised by Mr Johnson—where there's a family member and there's a disagreement, or a substitute decision-maker and there's a disagreement, with what the health practitioner wants to do, then they can all apply to the board. But where the health practitioner and the family agree on a person who has been deemed incapable, and that incapable person has the right to appeal, how does that



incapable person know they've been deemed incapable? Because they're not even told. So they could have surgery performed on them and they don't have the right to appeal on their own behalf. They don't even know. So how does section 35 protect them?

**Ms Auksi:** It wouldn't be section 35.

**Mr Ron Johnson:** It would be a different—

**Mrs Caplan:** But they're listed here in subsection 35(2).

**Ms Perun:** Yes, under section 35 they're given notice, they are parties, but again, in that issue that you've raised, if they don't agree that they're incapable and someone's making decisions on their behalf, the issue is, how would they know how to apply to the board? As you've heard Gilbert say, you'll hear from the colleges that they say that they'll take on that responsibility in providing direction to their members as to what kind of information should be provided and what is appropriate.

**Mr Clement:** Could I just hopscotch from Mrs Caplan's point and probe a bit on this? On the interplay of the statutory law and the common law, there is a duty of care that health practitioners are obligated to provide. Is that correct?

**Ms Perun:** There's a duty of care, yes.

**Mr Clement:** How does that interplay with the situation that Mrs Caplan has outlined? I guess none of us is concerned where the individual is not advised that he or she is deemed to be in an incapacity situation and then everything goes well. There's been no harm done. No one's going to sue anybody else because they got better. But I guess it's the case where things don't go well and then there's an allocation in our society as to who is paying for the mishap, I suppose, if I can put it that way. Is that where the duty of care comes in? Is that where the College of Physicians and Surgeons is saying, "Yes, if things go wrong and if a doctor does the incorrect thing without advising of rights and obligations," is that where it comes into play, or am I on the wrong track here?

**Mr Sharpe:** No, you're right, in part. There's a duty to look after people in a competent, reasonable way or that could result in negligence. There's also a duty at common law and in the statute to inform patients of various aspects of the treatment in order to permit them to make a decision. The issue I would raise, though, goes more to a practitioner having decided that the patient is not able to make that choice and they move to a substitute, and if the patient's not happy with that move, how do they know that they can challenge it?

In practical circumstances, this tends to arise usually where the patient is objecting to the fact that someone else is going to make a decision for them, or they may in fact not want the treatment at all, but they're not capable. Of course, there are shades and degrees of competency, and at times people can fluctuate in and out, and sometimes it makes it very difficult for the provider in the facility to know who to turn to for this decision.

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But in these circumstances, again, the provider would be expected, where the person is saying, "I don't want to proceed with this," and they've been found incapable, as good practice to tell them: "Yes, there is something you

can do about it. You can challenge this decision if you want to," whether it's the professional themselves or the institution which they're in or other mechanisms for communicating that. We have many laws that provide rights and responsibilities on people without legislating various procedures for notifying them about those rights, but usually there is a multitude of mechanisms available to ensure that they know about it.

There were some assurances given in that regard, but as I say, as the minister indicated, perhaps the committee may find it useful to hear from a number of these regulatory organizations to determine whether that's sufficient.

**The Chair:** Thank you. We have one minute each for Mr Klees and Mrs Johns. If you'd go first, Mrs Johns.

**Mrs Helen Johns (Huron):** I just wanted to ask a question about family members and when they don't agree on the treatment for their loved one and they're both saying, "Hey, I think it should be done a different way." When that happens, even if they're at the same level or whatever, that then goes to the appeal board and is resolved. Can you tell us kind of the process of how two individuals would deal with a disagreement about how the process should work for their loved one?

**Mr Sharpe:** For one second before we get into that, again, what providers tell us is, rather than creating immediately an adversarial stance where one must go to some kind of a tie-breaker, in many circumstances the practitioner will work with the family and the extended family to come to a reasoned choice. No one wants a confrontation in that setting, if it can be avoided. But there is a process.

**Ms Perun:** Well, there isn't really that much of a process. Where the two people are in disagreement and they cannot agree, the act provides that the public guardian and trustee shall make the decision in their stead. That's provided in subsection 18(6). Yes, we have heard from the providers that often it works very well to say to the two sisters who are disagreeing about the care of their mother, "Look, if you two can't come to an agreement, then we're required by legislation to turn to the public guardian and trustee," and often then it sort of triggers them into sort of thinking, "Oh well, we better resolve this." But ultimately there is a mechanism whereby the public guardian and trustee will become involved. I don't want to speak for that office, but I understand that part of their policy is to facilitate a resolution, if they can.

**Ms Auksi:** If I can, may I say a little bit more about that? Because if the incapable person appears to have a choice as to who they'd prefer to have make the decision, then the incapable person can also apply to the board to have their choice of decision-maker appointed.

**Mrs Boyd:** Except they don't know that they have that right.

**Ms Auksi:** But the thing is, in that situation the health practitioner could tell them—

**The Chair:** Excuse me. Mr Klees has the floor, please.

**Mr Klees:** Thank you. I'd just like to return very briefly to the previous point that was under discussion. I think it really deals with the issue of disclosure to the patient in the circumstance where the attending physici-



ian's made a decision that they're incapable. I don't think there's disagreement in this room among committee members that it's very important that the patient have full disclosure. I think what you're suggesting, Mr Sharpe, is that we would look to some of the delegations here from perhaps the College of Physicians and Surgeons and others to help us work that out practically, because I too am very concerned that a patient have that full disclosure and also have the opportunity to appeal that decision. I think the question now is, do we leave that to regulation or, as legislators, do we ensure that that principle is entrenched up front in legislation? It's something that we really should give very serious thought to. Do you have any suggestions yourself from the discussions that you've had with some of the colleges and so on as to the direction that they may be heading and what we as committee members should be looking for?

**Mr Sharpe:** I don't want to prejudge their presentation in any way, but I believe the minister did flag the issue in a fairly neutral way to say that he is open to listening as to whether or not the committee is satisfied that these regulatory bodies and other mechanisms—perhaps the chair of the review board is going to appear. In some jurisdictions, like Australia, I believe that the review board also has a role of information and education. I know that he feels fairly strongly about that.

So if the committee is satisfied that these other mechanisms are sufficient and it's not necessary to legislate rules to direct providers and others to tell them precisely what must be said in what circumstances with all patients, then that will be the decision. If, on the other hand, there is a lack of satisfaction with the explanation on the protections that are relatively informal, as opposed to legislating, there may be some need to look to alternative language that isn't so specific as to tie one's hands in every circumstance but still would ensure that basic information is provided.

**The Chair:** Witnesses, I thank you very much.

#### MINISTRY OF THE ATTORNEY GENERAL

**The Chair:** We are now going to hear from the Ministry of the Attorney General, Ms Spinks and Mr Chalke, I believe. You have our undivided attention.

**Mr Jay Chalke:** Good afternoon. I am Jay Chalke, the deputy public guardian and trustee. With me is Trudy Spinks, legal counsel in the office of the public guardian and trustee. We would like to take you through the amendments related to part III of Bill 19, those that relate to the amendments to the Substitute Decisions Act. Before that, we thought it would be useful to trace for a few minutes, in a manner somewhat similar to that which Mr Sharpe did, a bit of the history of the laws related to substitute decision-making for incapable adults in situations other than in health care.

Before we do that, though, I thought it might be a little bit useful to just take a minute to describe the difference between the statute you just heard about, the Health Care Consent Act, and the Substitute Decisions Act, because people often get confused. They both relate to a similar and yet somewhat different topic.

The Health Care Consent Act and its predecessor, the Consent to Treatment Act, deal with a particular set of circumstances and a particular regime for substitute decision-making for people who are incapable with respect to making decisions related to their health care. As a specific scheme, where it applies it prevails. However, some people require more extensive decision-making on their behalf, and that more extensive decision-making may relate to a broader range of decisions, that is to say, decisions related to what would happen to their property—say, their house or their bank accounts—where they are going to live, their legal rights, their causes of action they may have—they may be a party to a matrimonial dispute—who's going to look after that sort of thing.

Also, people may require more extensive substitute decision-making authority because it relates to a longer-term situation. It may not be a sort of one-off treatment decision but may relate to a long-term duration of incapacity. The health care consent regimes are designed and are built around the concept of essentially one-off decision-making as opposed to long-term decision-making. The Substitute Decisions Act is the statute that addresses this more long-term or comprehensive and more broad decision-making authority.

Now I'll just discuss the history for a few minutes. It's important to understand that while the Substitute Decisions Act is in itself a new statute, it is not new to have a substitute decision-making regime for people who we now refer to as incapable adults. I think it would assist the committee to hear a little bit of that so you can put your consideration of this bill into some context.

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Historically, the monarch—that is, the King or Queen—had constitutional responsibility for the affairs of people who were incapable through the doctor and what is known as *parens patriae*. This doctrine arose in order to protect incapable people as well as to ensure in a pragmatic sense that there was someone who could deal with the property of people who were incapable so that in effect it wasn't ownerless and nothing could happen to it and no one was looking after it. So it started with essentially all that responsibility vesting in the monarch.

In the 19th century, there started to be statutory measures put in place in order to allow private individuals to make substitute decisions on behalf of others and there was an example of that in the 19th century known as the Lunacy Act. A more recent incarnation was something called the Mental Incompetency Act, which was passed in Ontario in the early part of this century and remained the law until 1995. The Mental Incompetency Act established a scheme of court appointment for private substitute decision-makers, known under that act as committees. It did so through the creation of a court process in which an individual's competence was determined by a judge.

There are a number of problems and issues related to the Mental Incompetency Act and Ms Spinks will discuss them a little later when she refers to a report known as the Fram report, but just to know there was this one process that was court-based. At the same time that the Mental Incompetency Act existed and provided this court scheme, there was the development, the recognition, that



there needed to be a more expedited process for the appointment of a substitute decision-maker for property that belonged to patients of what we now call or what are now referred to as psychiatric hospitals.

This expedited scheme was necessitated for a number of reasons, one of which, for example, was that many such people lacked sufficient assets to justify a court process, to justify the costs that related to that, but still required someone to look after that property, or because they had no individual who was prepared to go through the expense and burden of applying to court and then carrying out the responsibilities of being a court-appointed committee.

In any event, a process was created by which a doctor would certify that an individual was incapable of managing their finances. That was first introduced for inpatients of psychiatric hospitals and then subsequently was extended to outpatients of psychiatric hospitals under the Mental Health Act.

This process provided that in the event that a doctor found an individual was not capable of managing their finances, the office of the public trustee, as it was then known, would be the committee of their estate and that was done directly by statute. But that was the only organization that could become the committee of an estate through that process. So we have those two processes.

At the same time, there was really a third process that grew up. That involved a growing recognition or growing interest among the public to develop a scheme by which individuals could preplan for the possibility that they would become incapable and do so in a way that people have always planned for the certainty that they will die, through the creation of a will. This became known as the creation of a continuing power of attorney.

Historically, the law considered a power of attorney to terminate on somebody becoming incapable. In other words, historically it was not possible to create a power of attorney that survived your own incapacity and, therefore, historically someone could only get substitute decision-making rights for property through this court process or through the expedited process for psychiatric patients that I described. So prior planning for your own future incapacity wasn't possible.

In 1979 an amendment was made to the Powers of Attorney Act to permit a power of attorney to survive subsequent mental incapacity and thereby permit individuals to start to preplan for incapacity. This then created an issue we still struggle with to this day, which is the issue related to what happens when someone falls into more than one of these schemes. They plan for their future incapacity but they're also found, for example, to be incapable and certified under the Mental Health Act process.

From 1979 to 1984 the Powers of Attorney Act provided that while a power of attorney could survive legal incapacity, the power of attorney itself was terminated if the public trustee was made committee of the estate. In other words, during that period of time, the public trustee's trusteeship prevailed over the continuing power of attorney.

In 1984 subsequent amendments were made to the Powers of Attorney Act that were made to essentially change the way this conflict between the two regimes was resolved and provided that if a particular form of words was used, and if the attorney followed a particular practice, then the attorney could oust the jurisdiction of the public trustee that had arisen under the Mental Health Act. So from 1984 to 1995 the power of attorney prevailed over the public trustee's statutory trusteeship.

There were these three essentially independent schemes, all of which dealt with substitute decision-making for incapable adults in a rather patchwork or piecemeal effect—and I should say almost exclusively, not entirely exclusively—but almost exclusively dealt with property matters. Significant gaps remained in this legislative structure and there were a number of issues that were undealt with.

The government established a number of reviews of the issues related to substitute decision-making for incapable adults as well as related matters, and these studies took place through the 1980s, particularly the latter half of the 1980s. You've heard reference already to the work of the Fram committee and I think Ms Spinks will now just give you a bit of a highlight of what the Fram committee identified as the issues that were required for the purpose of law reform at that time.

**Ms Trudy Spinks:** I think Mr Chalke has highlighted the main one and the most prominent one, which is that the legislation prior to the Substitute Decisions Act was extremely fragmented and you had a lot of statutes covering territory that was very much related and very difficult for people therefore to understand, and a lot of conflicting systems.

Another key issue the Fram report identified is, how do you define mental incapacity for the purpose of making decisions? The old test was primarily modelled on the type of disease that you had. If a person was diagnosed with certain things, then they were more likely to be believed to be incapable, whereas I think the more modern thinking, certainly at the time the Fram report was being done, was that you should be focusing on the issue of what a person is capable of understanding, what kind of information they can process and whether they can appreciate the consequences of decisions; what the cause is, is not really the issue. That was a problem with the definition.

Another issue with respect to mental incapacity was that the law tended to focus on an all-or-nothing proposition that you would either be found capable or incapable, whereas I think it was recognized that people have different levels of decision-making for different types of activities. The kind of decision-making capacity that you need perhaps to make decisions of a routine nature in the course of one's life, perhaps about clothing or hygiene, are not necessarily what you would need if you were making decisions about serious medical issues.

The absence of any mechanism to plan ahead for personal care decision-making was a key missing element in the legislation, particularly in light of the fact that at the time in the States the issue of advance health care directives, which are not the same as, but are similar to, powers of attorney for personal care, had become very



prominent. In fact, almost all the US states have them, and I think this brought to the fore that people in Ontario didn't have that opportunity.

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The provision of information about people's rights, which under the Mental Incompetency Act was completely absent and limited under the Mental Health Act: The absence of a non-court process for people who were not in the psychiatric system to obtain guardianship of property was identified as a missing element, as well as the fact that the only body that could be applied in this more expeditious manner was the public guardian and trustee's office, where in fact I think it was widely understood that it was better wherever possible for family to be placed in that position as long as they were suitable to do so.

The absence of any mechanism to investigate abuse or neglect, sometimes self-neglect, of incapable people: Certainly a number of inquests brought that issue to a head. None of the public agencies felt they had the mandate to address the problems and there were some extremely tragic cases that no one felt they were obliged to deal with. I don't think it was from a lack of good intent on anyone's part, but there was a clear lack of designation of responsibility in the law.

I think, as well, an absence of clarity around many of the rules about what guardians were supposed to do and not do, and how they would be held accountable and so forth, tended to engender a lot of legal debate, and it was felt that the legislation wasn't specific enough to provide proper guidance.

Finally, the old legislation tended to be very court-oriented, that everything was a matter of a court hearing. When those issues were examined it was questioned why, if there was no contest to a particular thing, if all the proper people had been notified and so forth and capacity wasn't at issue, people should be forced to go through in-court hearings processes each time. So a need to simplify those processes was identified.

**Mr Chalke:** Just to pick the story up from there, the Substitute Decisions Act was then the government's response to the report of the Fram committee. It was introduced in 1991 and received hearings through 1991 and 1992 and received third reading in December 1992 and was proclaimed on April 3, 1995.

The purpose of part III of Bill 19 is to introduce changes to the Substitute Decisions Act which preserve the improvements that were made to create this comprehensive scheme of substitute decision-making, while at the same time making the statute more practical and workable. I think that has been the primary issue related to this particular piece of legislation, and to make sure that those people who do undertake responsibilities in this area can do so in a practical way.

I think we're now going to try and turn specifically to Bill 19 and Ms Spinks is going to take you through some of the major changes and we'll try and give you some examples about how that might play out under Bill 19.

**Ms Spinks:** In the interests of time, I'm clearly not going to go into detail about every single amendment that's in part III, so I'm going to hit what I think are the highlights and perhaps there'll be questions about other aspects at the end.

With respect to how a power of attorney is made, whether it's a power of attorney for a property or for personal care, one of the issues that has been raised is a provision in the current legislation that says witnesses are not to sign the document unless they have no reason to believe that the person is incapable. This has engendered legal debate ad nauseam as to the meaning of that. The intent of the statute was not to require witnesses who may be clerical staff in a law office, or a neighbour and so forth to engage in an inquiry as to the person's capacity. It wasn't meant to require that they warrant the capacity of the grantor, but there's been some question about that, so the section is repealed and in that way it is much more like the ways wills are signed.

In addition, the current legislation added a restriction that was not there prior to the SDA, which said that the children of the grantor—the grantor is the person who signs the power of attorney—are excluded from acting as witnesses. This wasn't the case prior to SDA. There has been in practice a feeling that in terms of the workability of that, people often don't want to take that issue outside their family. There isn't automatic conflict of interest in children, because they are not automatic heirs; only in the case of an intestacy would they fall into that category. The bar on the grantor's spouse acting as a witness has been retained because, just by virtue of the fact that they're married, they have certain legal claims on money and have an interest. The prohibition on the grantor's children has been deleted.

The clause which says that a power of attorney is terminated when the public guardian and trustee is appointed, which has been the source of some concern from the public, has been deleted. That will permit a power of attorney to endure regardless of the fact that a finding of incapacity might be made that would otherwise lead to guardianship occurring. That will essentially mean that powers of attorney will continue operating where they wouldn't, technically, today. You'll find that provision in section 8 of Bill 19.

Section 10 addresses a process called statutory guardianship. The minister spoke about that. That is essentially the non-court process for getting a guardian of property in place. There are several key changes in this particular section, the first of which is that there are provisions in here that will prevent the process being started. The process leads, hopefully, to the appointment of a family member as a replacement, but does lead to the public guardian and trustee in order that that process can take place. People have been concerned about the process even being commenced when power of attorney has already been made. I think it clearly was always the intent of the statute that that's the way it would operate, and the provisions here clarify that so that it puts up a Stop sign in that case.

The role of the advocate has been removed. The role of the advocate here, of course, was to provide information about people's rights in relation to the statutory guardianship, and since the Advocacy Act is being repealed there obviously has to be a replacement for that function. The legislation puts the mandatory obligation on the public guardian and trustee's office to provide that information. The information given would be about the



individual's rights, having been assessed as incapable. The new section will say they have a right to appeal the finding of incapacity to the Consent and Capacity Review Board. This is very similar to the way the Mental Health Act functioned prior to SDA and continues to for in-patients of psychiatric facilities.

A key amendment you'll find in section 10 of page 5 of your bill. It incorporates a new clause, section 16.1. It says that should it occur that the public guardian and trustee is appointed, or perhaps a replacement after the appointment of the office, and it turns out that there is a pre-existing power of attorney—in other words, someone slipped through the crack, probably in a quite well-meaning way or for reasons that are understandable; for example, the attorney isn't known at the time or the documents haven't been found or a certificate is issued under the Mental Health Act, which has a mandatory process—the new clause will provide that the authority of the statutory guardian will be terminated in favour of the authority of the person holding the power of attorney. That again is much more consistent with the way the previous legislation operated.

**1650**

Termination of statutory guardianship is at present a unilateral right of the incapable person. Essentially, that means that person can say, "I don't want the guardianship any more," and it's over as of that moment, subject to, in the present legislation, having an advocate confirm that. That section has been changed, and the guardianship will be terminated upon a finding of capacity. If an assessor or, in the case of someone who's been certified in the psychiatric system, a physician working for a psychiatric facility gives an opinion saying the individual is capable, that will be sufficient to end the guardianship. There will be a right of appeal provided in those cases where people don't like the results of the assessment they obtained for that purpose and want to have the Consent and Capacity Review Board look at the issue.

Section 11 deals with the procedure for replacing the public guardian and trustee. Formerly, that was open to a limited category of people, basically immediate family. Under the proposed amendments, that will be open to any relative and a number of other people; namely, a person holding a power of attorney who has a limited power of attorney that only covers part of the property, or a trust company where a spouse or partner has given written consent. So it's a much broader right of access to that particular process. Some of the paperwork that was previously required would no longer be necessary, and the issue of security has been addressed here. At present it's mandatory for every estate over \$50,000 and would now under this scheme be an issue of discretion, so the circumstances of the individual case could be assessed on a case-by-case basis rather than having an arbitrary rule applying to everyone.

Section 16, you'll note, addresses some changes to the investigation function of the public guardian and trustee. At the moment, the legislation is fairly broad-reaching in terms of the legal obligation it places on the public guardian and trustee's office; it basically says to investigate every allegation of harm to an incapable person. There isn't within the legislation as it's drafted today any

scope to take two steps towards that issue: to discover that there is a better alternative than guardianship or continuing involvement of the public guardian and trustee, whether it be family, for example, who are able to deal with the issue, or referral to another kind of social agency that can handle the matter. There really isn't the scope within the legislation as it's drafted to do that; it implies that the office needs to go through the full process of an investigation, so there has been some language introduced there to clarify that issue.

The matter of the records acquired during those investigations has also been addressed. As a very practical matter, our office has found that the kinds of matters we become involved with often relate to people who are marginal or borderline capacity and who, although they may not be sufficiently at risk today to warrant guardianship, that picture often changes in three months or four months. It's extremely difficult. At the moment the legislation requires the office to destroy any records acquired during the investigation, which means opening the issue up all over again, going back to all the same care providers, perhaps going back and intruding on the individual again. It's not only inefficient, but it can be an offensive process. The amendment would allow the office to keep records for a maximum of three years, assuming no further activity has taken place within that time.

The amendments will remove a requirement that guardians of property prepare an annual financial report. Essentially, the legislation as it's written today requires two steps: one to keep accounts and records, and the other to prepare this annual report, a report which isn't, in the law as it's written, required to go anywhere. It's a duplication of effort and it does unnecessarily complicate matters, so the proposal is to simply require the keeping of accounts. You'll note that the regulations will spell out how those accounts are to be kept and what should be in them and so forth.

The reason that issue has been left in regulation-making authority is because it's a highly procedural issue and it can change what needs to be recorded. Once you have two or three years' experience with guardianship under this new scheme, there might be other actually relevant things that the court is asking about that were not asked for in the records here. The regulation-making authority allows the flexibility to change that.

Moving into the area of personal care decision-making, I will just note that the changes to powers of attorney for personal care—the requirements for making them, how they're made, the witnessing requirements and the exclusions for certain classes of witnesses—are the same as for powers of attorney for personal care. Rather than repeat that, I'll just note that's the case.

One of the key amendments concerns how you use a power of attorney for personal care, which unlike a power of attorney for property can never be used unless the person is actually incapable. Under the current scheme there is a process, and I think the minister described it in his remarks, involving assessors and advocates in the process of validation, getting approval from our office.

That process would under these amendments be eliminated. Instead, a finding of incapacity made under



the Health Care Consent Act by a health care practitioner would be sufficient to trigger the authority to make decisions under that legislation, or if the matter falls outside the Health Care Consent Act, it's really up to the attorney, that is, the substitute decision-maker chosen by the individual when they're capable; it's a matter of their opinion of whether they have grounds to believe the person is now incapable of making decisions.

All that of course is subject to the right of the person who makes the power of attorney when they're capable to write in a different kind of requirement, and if that's what a person chooses to do, they are free to do so. They could, for example, say: "That's not good enough for me. I would like to have a letter from my family doctor before this can be used." Other people might say: "I've total, implicit trust, and I don't want to put any road-blocks in the way of anything. I'm making this decision to give you this authority and not to add any complications." It's a matter of choice and it's a matter of people being able to tailor it the way they see is best for them in their particular situation.

There is a special kind of power of attorney that the Substitute Decisions Act addresses. Certainly it was there in the original bill, and it's quite interesting that we're the only jurisdiction that has such a document. Essentially, what this special power of attorney does is allow people to write in fairly serious waivers of rights they would normally have, such as the right to appeal certain things, the right not to be forcibly admitted without a court order. Some people have the kind of illness that fluctuates and they want to be able, when they're capable, to make the decision that they'd like to give this sort of authority to another person because they foresee that they will lack insight at the time of incapacity.

That vehicle is being retained in the proposed amendments, but the process of using it is being simplified significantly. Essentially, what's being removed is the requirement of registration with the public guardian and trustee, the requirement for subsequent validation—that's opinions from assessors—and in its place, what is here is a requirement that the key issue is that the mental capacity of the person who signs this document at the time they assign these rights needs to be addressed, so there will continue to be a requirement of an assessment of capacity that accompanies that document, as well as the person who signs it having acknowledged that they understand what it is they're doing.

1700

The particular waivers that are listed here in that section have been put together as a package. Basically, the approach is that most people who want to waive certain rights would likely want to waive others, but most importantly these are documents which a third party, for example a psychiatrist, must look at to decide whether or not they have the authority to do what the attorney, the substitute, is telling them they can do. It's extremely difficult if everybody is writing these things in a different way. It allows the practitioner or the third party to actually know that this is what this document means if it's written in a prescribed way. That is the reason for that particular requirement.

There are similar changes around the investigation function in the area of personal care. They are sufficiently the same as those in the area of property that I won't go into them, with one exception: There is a difference in the SDA as it reads today between temporary guardianship applications—that's where the public guardian and trustee goes to court to seek short-term authority in an extreme case—and today the Substitute Decisions Act says if it's a personal care matter, that order can only last for seven days and then you must go back to the judge and you must get an extension or termination.

What's happened in practice is that that isn't a long enough period of time, and the courts and the office and the caregivers are finding it frustrating. It doesn't allow enough time to actually address the problem that's been identified. So it will still be limited to up to 90 days but it will be within the discretion of the judge, who we think has sufficient discretion and judgement to decide what is best in the particular circumstances, whether it needs to be two days or seven days or 40 days.

There is in the current legislation a requirement that the PGT keep a register of certain types of substitute decision-making appointments. The purpose of that is so that third parties like doctors or banks could find out if someone has a legal decision-maker appointed and get hold of him or her. So it requires certain contact information and so forth. You'll note that in the amendments that section has been deleted, and instead, there is regulation-making authority. The reason for that is that a number of health professionals and people and members of the legal profession have said, "You know, there's a lot of potential uses for the register in terms of people voluntarily being able to record information that they want to have accessible."

Obviously, there are a number of issues that would need to be addressed before that could be done, but the current legislation does not allow the flexibility. So with regulation-making authority, there would be flexibility to consider that option, assuming that all of the necessary consultations and discussions of all the implications and the stakeholders and so forth were reviewed and the appropriate model could be designed. That's why the move into the regulations.

The mediation function of the public guardian and trustee—I think it was mentioned earlier in the presentation that the Ministry of Health did. At the present time, it says if there is a substitute who makes property decisions and a substitute who makes personal care decisions—I think Ms Boyd raised this issue—then the public guardian and trustee "shall mediate." Mediation is something that I think by definition requires two willing parties, so it's suggested that the "shall" is not an appropriate term here and that also there might be other situations, for example joint attorneys, two people who are acting for the same type of decision-making, who need some access to resolve their disputes. So that section has been amended accordingly.

Just on that point I would like to note that disputes in these particular areas, the office, in working on a day-to-day basis with people in this who have substitute decision-making authority, found that that issue doesn't arise very often in practice because usually it's the same



person who makes personal care decisions and property decisions—usually. Sometimes it's different people, and usually they get along and resolve their differences. There is the odd case where that doesn't happen. Those cases ultimately, if they can't be resolved, end up in court. That's traditionally the remedy.

Finally, I just want to address some of the regulation-making authority issues. The new regulation-making authority that's been added to prescribe standards for capacity assessments, to regulate fees—I just want to caution that no decisions have been made on these issues. It's intended that no decisions would be made until full consultation and analysis of all of the implications were carried out.

As was discussed earlier, there is regulation-making authority to authorize "a member of a college as defined in the Regulated Health Professions Act...or a person who provides health care or residential, social, training or support services...to disclose personal information" in specified circumstances. Those circumstances are for the purpose of assisting an assessor who is obliged to perform an assessment based on the fullest information possible in order that a person not be found incapable when they are capable. That's the purpose underlying that to a person who is making a guardianship application.

In practice, over the past decades people—usually family members—have been going to court and asking the court to appoint a guardian. The most typical situation, for example, is a daughter with an elderly mother, where the elderly mother is often under care, has been for some time, and there is ready access to a family physician who wants to enable the protection of this person. Often family involvement for guardianship is precipitated by a need to protect the individual from harm or neglect, self-neglect or abuse, so there is a protective element there. In the vast majority of cases, doctors who have been treating the incapable person are quite willing to provide a report to submit to the court with the application, but they're quite concerned about their confidentiality rules and whether they are authorized to do that. That is the rationale behind this. It certainly wouldn't compel a practitioner. It's not compulsory; it's an authorization, and it's a regulation-making authority only, which will of course be discussed with the Information and Privacy Commissioner.

The final class of people to whom that disclosure might apply would be to the public guardian and trustee in the course of conducting an investigation of harm. We have run into several situations where people in the community who may be governed by a municipal freedom of information act—community agency workers or health care professionals—want to identify a case of abuse of an incapable person and they feel they are not able to report that because of a barrier in terms of their confidentiality rules.

That essentially is the rationale, noting again that there is regulation-making authority, of course, to govern the use and disclosure of any personal information. So the regulations could be quite fulsome in terms of the restrictions they placed on how that information was used, bearing in mind that there is a whole class of people, as well as those I mentioned out there, who are

not covered by any confidentiality rules who could be brought in under this umbrella where they aren't today. I'm going to end on that note.

**The Chair:** Thank you, Ms Spinks. We have approximately six minutes for each caucus. Tomorrow we'll start a rotation but today you have the pleasure, Mrs Caplan, to proceed.

1710

**Mrs Caplan:** I'll go in reverse order, if that's okay, Trudy. I thought I'd start out by saying that substantially I agree with most of the substitute decision legislation, its goals as well as the way it's been implemented. I recognize that much of what is here responds to what's been learned, as to how the legislation has been implemented, and much of it would be considered technical.

There are a couple of glaring, I think, errors. I have real concern over the last provisions under clauses 90(3)(e.4) and (e.5) in particular because I don't think it's specific as to who the information can be disclosed to. It doesn't say public guardian and trustee; it doesn't say to a court. The way I read it, it authorizes "a member of a college as defined in the Regulated Health Professions Act...or a person who provides health care or residential, social, training" social support, "subject to the Mental Health Act and the Long-Term Care Act...but despite any other act or the regulation under any other act, to disclose personal information about a person."

You've said that's regulation-making ability. I think it's much too broad. I think it does threaten individual confidentiality, and while its intention may be good, I hope that you will reconsider and the government will reconsider what might be possible under those provisions.

The other point I would make is: For example, it says under subclause (ii), "to a person who has made or has stated in writing an intention to make an application to appoint a guardian of property or a guardian of the person, if the information is relevant to the application." That means anybody, with or without the consent of the individual, who applies to become a guardian, either for personal care or for property, can have all health information, including sensitive mental health information, disclosed to him or her.

I think that's much too broad. There's tremendous potential for abuse in a situation where family members with an adverse interest, if they're aware of this provision, particularly in the kinds of cases where people are in and out of capacity and incapacity, may—that's very dangerous and I have real concerns about it.

I know there's not time today to answer all those questions, so I'm just going to pose them in that way. I think the reg-making ability is much too broad governing the use and disclosure "of personal information obtained under the authority of a regulation." I'm not sure what that means or what the intent is, but I want to make sure that individual privacy is maintained and is paramount. There may be cases where disclosure may be in the individual's interests, but that case has to be made before the authority is granted. I'm not sure that having that broad reg-making ability is in anybody's best interests.

The other question, and perhaps you would have time: You've removed the prohibition against children as being witnesses on powers of attorney and there's no guaran-

tee—they may not even know. I think it might invalidate a power of attorney if it was discovered down the road that they had a financial interest. I wonder if you've considered that issue about allowing for children to pressure their parents into the signing of a power of attorney. I thought it was a protection for people when they could say to their kids, "Well, the law says you can't," you know; parents wouldn't want to say to their children, "No, I don't want you witnessing this." I'm wondering if you've thought about the pressure that could be brought to bear on vulnerable and aging parents who are given a power of attorney to sign by their children, who say, "Sign here and we'll witness this." Have you thought about that?

**Ms Spinks:** I take your point, that people shouldn't be acting as witnesses who might be in a conflict, who might pressure the person, but I don't know that you can identify children as a group automatically coming within that particular category. That could apply to an aunt or an uncle or a neighbour or a boyfriend or girlfriend and the same sorts of restrictions don't apply. So I'm not sure whether that generalization does.

**Mrs Caplan:** I guess the point is this: Where you have a friend or a neighbour or anyone—you do have the prohibition in here—they're less likely in a position to be able to influence. Am I correct in assuming there is a prohibition against anyone who would have a conflict of interest against signing a witness form, or not?

**Ms Spinks:** It's certainly not in the legislation.

**Mrs Caplan:** So there's no prohibition. Why would you not want a prohibition in the legislation for anyone who would have a conflict of interest?

**Ms Spinks:** I take your submission, your point, but I don't think that you could necessarily cover every single situation in a list that might encompass all of those potential human situations that might arise.

**Mrs Caplan:** It just seemed to me that you were protecting both parents and children from that kind of potential, because certainly the children have the most interest, and likely along with the spouse, in the order of hierarchy, and since you've said no to spouses, you're saying a spouse can't sign, I'm wondering why you're saying it's therefore okay for children to sign.

**Ms Spinks:** A spouse has a legal interest in the property just by virtue of their matrimonial relationship, and therefore it raises a legal issue, whereas children don't necessarily have an automatic legal interest in their parents' property. I think that perhaps people who practise in the area have not found that in the past this has led to—some may say yes, some may say no, but a lot say no, that it hasn't led to cases any more so than the neighbour or the aunt or the uncle.

**The Chair:** Thank you, Mrs Caplan.

**Mrs Caplan:** I'd like to have—

**The Chair:** No, no. We have to go to Mrs Boyd.

**Mrs Boyd:** Still on the conflict-of-interest issue, do I take it you've taken out the prohibition against a paid caregiver being the substitute decision-maker for personal care?

**Ms Spinks:** What the legislation says is that the courts, having considered the circumstances of the application, could appoint a paid service provider if there was no one

else who was suitable or willing in the circumstances, but it's only in the context of a court application where you have a judge looking at the material.

**Mrs Boyd:** Okay.

**Mr Chalke:** Just with respect to the last point about the witness is that the attorney can't witness the document. So the notion that someone who, say, has a potential conflict, the attorney can't be a witness. The power would have to be in favour of other people.

**Mrs Caplan:** Two children; one's the attorney and the other—

**Mrs Boyd:** Yes, that's the problem. Collusion is not unknown in these circumstances. It's a bit of a problem because we're talking about vulnerable people. We're not talking about people who are fully able to stand up for themselves in these circumstances. For the most part, we're talking about people who are very susceptible to coercion.

I guess it's just a worry. The provision was put in there in the first place because there were many representations made by many people that this was a real problem, and it's amazing that it appears to have changed, virtually overnight, that this is no longer a concern. I'm quite amazed.

The other issue I think is the whole issue of the checks and balances. It's really important to have some checks and balances in this kind of a situation, and I think removing the requirement to register or be just acknowledged to be the attorney by the public guardian and trustee is one of those. It seems to me that that's a bit of a problem, that when you add that to the problem that if there is a statutory guardian now the person themselves, the vulnerable person, can no longer refuse or terminate that. Is that not correct?

**Ms Spinks:** That's right.

**Mrs Boyd:** And that the powers of attorney for personal care can in fact now be exercised without the person ever having been informed. There's no information that they are in fact considered incapable.

**Ms Spinks:** I'd just like to clarify one issue on the termination. I said that is correct. In fact, the person can terminate the guardianship upon the production of evidence of capacity.

**Mrs Boyd:** And somebody informs them about how to do this, of course. Without any advocates, that doesn't happen, does it? That's the problem. These things may all be there, but once you take the advocates and the rights advisers out, what does it really mean to these vulnerable people? Do we expect the entire population of Ontario to be so well versed in this act that they're automatically going to know what their rights are at some point.

1720

**Mr Chalke:** Under subsection 16(6) of the act—you're referring to statutory guardianship—our office would be obligated to advise them that we had become the statutory guardian, and what the mechanism was for them—

**Mrs Boyd:** So the requirement is there for you.

**Mr Chalke:** Absolutely, for us to tell them. You're referring to statutory guardianship, so we will have an obligation.

**Mrs Boyd:** Okay. So unlike the other situations around consent to treatment, for you, in a statutory guardianship, that's written in.



**Mr Chalke:** Yes, it is.

**Mrs Boyd:** That's good to hear.

**Mr Tilson:** I had a quick question with respect to the forms that the former government sent out for powers of attorney. It appears that there are potential changes dealing specifically with personal care. In other words, a person who wants to specify in the power of attorney a method for determining whether he or she is incapable could, for example, state that that position could be confirmed by the person's own physician. I don't know whether this should be to the Health section or to your section, but are forms being prepared, or amendments, suggested clauses, that might assist members of the public so that somebody won't get deep-sixed, or whatever the expression is, when they want a particular position to take place? That's one example.

**Mr Chalke:** It is true that we have existing kits that we have distributed for the past almost two years now, and we are in the process of amending the kits. The kits will have to be changed to reflect the changes that are enacted by Bill 19. Kits that were completed prior to the proclamation of Bill 19 will survive and be legally effective following the proclamation of Bill 19.

**Mr Tilson:** I have one more question, dealing with a couple of the questions that were asked by my Liberal and NDP friends, and that was the possible conflict-of-interest issue of children, which I think Mrs Caplan mentioned. Surely there's some law that exists—in fact I'm almost positive there's some law—of an obligation of the attorney to act in an appropriate way that would perhaps relieve some of the concerns.

I suspect that Mrs Caplan is thinking of witnesses of wills, that you can't be a witness of a will if you're going to be a beneficiary. I assume that's the line of thinking that she's dealing with, and of course an attorney cannot witness a power of attorney, I don't think. But surely there's an obligation on the attorney to satisfy himself or herself that there's no collusion or other indiscretion.

**Mr Chalke:** An attorney is a fiduciary in law, which is about the highest duty that the law imposes on anybody, and can be called upon to justify their administration of the affairs of the incapable person, for example in a court or when, say, either the incapable person recovers or the attorney's care of the individual's affairs is terminated, perhaps either by recovery or even by when they die. The subsequent personal representative can call on them to account for what they did, down to the nickel.

**Mr Klees:** I'd like to just follow up on this same question with regard to conflict of interest for children. I'd be interested in the thinking behind removing children from the conflict role as the spouse is, particularly given the fact that children may well have a legal interest if the individual should die intestate. If there is a possibility that there is a conflict, why would we not take the safe route and leave them out? Surely people can find others to witness. What was the rationale, what was the thinking behind leaving them in, so that we have a better understanding of this issue?

**Ms Spinks:** Essentially, I think you're assuming that there is a conflict when there could be—you don't know, for example, what the terms of any person's will might be. There are all kinds of other sorts of conflicts potentially, other than being named in a will as a beneficiary, bearing in mind that the role of the attorney is to manage the assets of the individual during their lifetime and has nothing to do with the will. So that job ends at the date of death.

Clearly, there is a ban still on the attorney acting as a witness. Children could be heirs; they may not be heirs. A neighbour might be an heir. A completely unrelated friend might be an heir. They are not prohibited from acting as a witness. It's also a matter of privacy, that many people have complained about having to—in their reactions to issues around powers of attorney, that this is the kind of thing that they sometimes want to do within the framework of their own family rather than having to go out and have strangers, more or less.

**Mr Chalke:** I understand there are a number of private practitioners who are slated to come before this committee and it may be an issue that's worth exploring with them. It's an issue that many have said to us seems to cause a lot of burden and hassle to individuals, and given that it doesn't really deal with the range of conflicts that are out there and potentially out there—it merely picks one and assumes that that is and others aren't—that may be an issue that you want to consider.

**The Chair:** Thank you, Mr Chalke and Ms Spinks. I have asked that the subcommittee meet directly after this meeting. I thank you very much for your time today.

We are adjourning until tomorrow at 9 and we will be going until 5 o'clock, the last witness being the privacy commissioner. Thank you very much.

*The committee adjourned at 1727.*







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*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Oriole) for Mr Conway  
Clement, Tony (Brampton South / -Sud) for Mr Klees  
Grandmaître, Bernard (Ottawa East / -Est) for Mr Chiarelli  
Johns, Helen (Huron) for Mr Hudak  
Marchese, Rosario (Fort York) for Mr Hampton

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**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service





## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Tuesday 6 February 1996

# Journal des débats (Hansard)

Mardi 6 février 1996

## Standing committee on administration of justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

## Comité permanent de l'administration de la justice

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

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LEGISLATIVE ASSEMBLY OF ONTARIO  
STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Tuesday 6 February 1996

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO  
COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Mardi 6 février 1996

*The committee met at 0902 in room 151.*

ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, modifiant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

COLLEGE OF PHYSICIANS AND  
SURGEONS OF ONTARIO

**The Chair (Mr Gerry Martiniuk):** I call this meeting to order. This is the second day of the hearings of the administration of justice committee regarding Bill 19. This morning our first witnesses are representatives of the College of Physicians and Surgeons, who will have one half-hour, including questions, to make presentation. Identify yourselves for the purposes of Hansard.

**Dr Michael Dixon:** Good morning and thank you. I'm Michael Dixon. I'm the registrar of the College of Physicians and Surgeons, and with me is Dr Helen Gordon, the president of the college, and Dr Bernard Hammond, a public member from London.

Thank you for the opportunity to participate in this hearing on the Consent to Treatment Act. This is an act that in our view badly needs major change and improvement in order to make it work in the best interests of those in need of timely care.

We have said in the past that four broad areas of the act needed to be amended in order to make it workable: how to treat patients who cannot communicate meaningfully; the definitions of "severe suffering" and "serious bodily harm"; the definition of "treatment"; and the role and purpose of rights advisers. We are pleased to note that the proposed Health Care Consent Act does deal, in our view, appropriately and effectively with each of these concerns.

We intend to accomplish three things in the brief time we have today. First, we want to put the existing Consent to Treatment Act and the college's concerns about it into

a historical context; second, we want to give a specific example of how the existing act compromises patients' care; third, we will indicate how we think the proposed Health Care Consent Act solves most of the problems created by the existing Consent to Treatment Act.

**Dr Helen Gordon:** The college applauds and strongly supports the proposed amendments, because we think they're long overdue, we think they're clear and we think they are in the best interests of patients. The mandate of the College of Physicians and Surgeons is to protect the public and guide the medical profession in Ontario. That task, made much more difficult by the current act, is made much easier by the proposed amendments.

We think the amendments restore the important and necessary balance between health care providers and patients and the balance between the consumer's right to choose and the practitioner's ability to provide good quality of care.

It has been more than three and a half years since this college first expressed serious concerns about the Consent to Treatment Act. In February 1992 senior college representatives appeared before the standing committee on administration of justice. At that time, the college noted that the Minister of Health of the day, Frances Lankin, said that she hoped that "common sense would prevail in applying the legislation." The college was of the view that "common sense cannot apply in the absence of clear legislative direction."

So confused and confusing is the current act that the college spoke out forcefully and clearly several times during the past three and a half years. College officials appeared and spoke at a second round of public hearings before the justice committee in August 1992. They noted that while the government of the day had made significant amendments to its own legislation since the first round of public hearings, the consent and advocacy acts were still not ready to enter the real world of Ontario's front-line health care system. A month later, in September 1992, the college stated publicly that the consent-to-treatment legislation was so seriously flawed that it could endanger members of the public in need of medical care.

In short, the bureaucratic complexities of the consent-to-treatment legislation forced health care workers to observe technical legal compliance above all else. It ties up the interests of vulnerable and incapable people in legalistic red tape and it prevents health care practitioners from acting in accordance with the judgement that they are trained to deliver.

**Dr Bernard Hammond:** The college, long before the Consent to Treatment Act became law, instructed its members regarding informed consent by stating: "The patient has the right to accept or reject any investigative

procedure or treatment offered. This right can only be exercised meaningfully if the patient has been given a fair explanation of what is proposed to be done and what the potential benefits and risks are."

It's worth noting that this standard is supported by the common law, which the Consent to Treatment Act was supposed to codify, protect and enhance.

Let us give you a specific example of why the Consent to Treatment Act doesn't work properly. We used this example at a news conference in June 1994 to explain to the public through the media what the college's objections to the Consent to Treatment Act were.

We will also show the committee, using the same example, why we believe the proposed amendments will solve the problems we will describe and lead to better patient care and fewer delays, delays which are costly in both financial and human terms.

We have warned since the outset that the Consent to Treatment Act does not deal in a realistic way with patients who are incapable of giving consent, but who cannot interact in a meaningful way because they are confused, demented or semiconscious. This is a significant percentage of persons who are incapable.

We developed a scenario involving an elderly man—call him Mr Jones—who, having been unable to urinate for several hours and clearly in increasing discomfort, is brought to the emergency unit of a hospital by his middle-aged daughter. Because the doctor cannot understand Mr Jones's response when he was asked for his consent to perform a catheterization to relieve his problem, a complicated, confusing and time-consuming process falls into place under consent to treatment.

0910

**Dr Gordon:** First of all, the doctor tells the incoherent Mr Jones that he finds him incapable of consenting, then he reads Mr Jones the government-supplied statement outlining his right to appeal the finding of incapacity, and then he tells him that a family member or the patient's personal substitute must be called on to make the decision for him. The doctor also informs Mr Jones that he is entitled to meet a government-appointed rights adviser who will explain his rights. Then the doctor gives the patient a printed notice provided by the government which outlines the rights the doctor just read to Mr Jones.

The doctor then asks Mr Jones if he wants to see a rights adviser and, since Mr Jones's response to this question is no more intelligible than his response to the earlier question about treatment, the doctor calls on a rights adviser just to be on the safe side. The rights adviser arrives at the hospital, perhaps hours later, reads Mr Jones his rights and finds Mr Jones no more coherent than did the doctor.

During this delay the doctor is not permitted to treat Mr Jones or to offer him relief unless he consents or unless he experiences what the Consent to Treatment Act calls "severe suffering" or unless he's at risk of suffering what the act calls "serious bodily harm."

Throughout this whole process Mr Jones's daughter, who brought her father to the hospital in the first place, is finding it increasingly difficult to watch her father suffer and pleads with the doctor simply to do the catheterization. The doctor is unwilling to agree with her

request because of his uncertainty as to Mr Jones's capacity and the possibility of facing a professional misconduct charge by the college if he does.

Once the rights adviser has left, the doctor can ask Mr Jones's daughter if her father has appointed an attorney for personal care under the Substitute Decisions Act. If he has, that person can now be called in to make the decision regarding the treatment on Mr Jones's behalf. If Mr Jones has not appointed such a person, and if his wife or partner is not present and his daughter has no reason to believe that his wife or partner would be available, then and only then can Mr Jones's daughter give consent for the treatment of her elderly father.

I'm sure members of the committee will agree that this is a fairly horrific scenario. We can assure you that it's a very realistic and not uncommon one in emergency rooms across the province.

**Dr Hammond:** Under the proposed Health Care Consent Act, here is how the Mr Jones scenario would unfold: He would be brought into the hospital by his daughter, examined by the doctor and determined that he was suffering from acute urinary retention. The doctor would then tell Mr Jones that the treatment would involve catheterization and would ask Mr Jones for his consent. If Mr Jones's response were incoherent or unintelligible, the doctor could then turn to the daughter who brought her father in and seek her consent on his behalf. In the alternative, the doctor could, under the amended act, decide that Mr Jones appeared to be suffering and could catheterize him and relieve his pain.

We submit to you that this is the desired outcome for the patient and that hours of delay coupled with miles of bureaucratic red tape and suffering is not.

On behalf of the medical profession in Ontario and the public, the College of Physicians and Surgeons welcomes these changes. We think the new act deals with the issue of informed consent in a practical and realistic way while at the same time maintaining the right of patients to make informed choices about their own medical care.

**The Chair:** We'll now have questions, starting with the third party.

**Mrs Marion Boyd (London Centre):** You've presented a very interesting scenario. However, I'm surprised in the first example you give where in the one paragraph you talk about the doctor not being able to do anything unless the patient is suffering and the daughter being worried about the patient suffering. What was the problem in treating that as an emergency under the current act?

That is really the crux of the matter, because most of the examples that have been brought forward by the OMA and by the college—from the point of view of many observers, there is great puzzlement as to why the procedure could not go forward under an emergency because of the suffering of the patient. This is an example that strikes me as being very similar.

I'm just curious as to why you feel that would not be possible. It is in the second scenario, when you talk about the current act. I'm just totally puzzled and have been from the beginning why there is so much angst under those circumstances. If this person's bladder has been full



for some time, we all have reason to know that's extreme suffering.

**Dr Dixon:** I think this is really the issue. The problem is the determination of the meaning of words and that they are not defined. The proposed act makes it very clear that it's "apparent suffering," and we think that's a substantial improvement. "Serious suffering" is in the eyes of either the beholder or the person experiencing the suffering and it's not clear which one should base the assessment on. We think this clarification is very welcomed and will alleviate the problem that the scenario proposed.

**Mrs Boyd:** If there were ever any dispute in the long run, it would be the same kind of judgement call that a physician would have to make in either case. If it's an apparent suffering and someone then got angry about what happened—for example, in the course of this, if the catheter punctures the side of the urethra and complications arise, the physician's in the same kind of situation they would be in the original case. I'm not saying "apparent suffering" doesn't ease some of those concerns; I think it is better wording.

I'm just saying that I think there has been a great deal of fearmongering around what the other one did that really was not necessary in terms of the judgement that physicians would do. I think there are many people in the province who, since this act came into place, have really not experienced the kind of angst that has kept being presented. We have not seen a whole lot of cases brought forward, that have been able to be verified, where in fact bad treatment resulted as a result of the act. I think that's kind of a confusing issue.

Given that the government has decided to take away the rights advisers, in your second scenario, under the new act do you not think that Mr Jones should be told by the physician when he is unable to answer his question that the physician considers him to be incapable and therefore is going to turn to his next of kin, his daughter who is available, to get her permission?

**Dr Dixon:** I think it all depends on the circumstance, and this is why I think it's so important to have some discretion on the part of the caregiver. If the patient is significantly incapacitated and unable to understand anything of significance, it's not very helpful to enter into an attempted dialogue by beginning to tell the patient that they're incapable and that you have to discuss this with the substitute. On the other hand, if the patient is only marginally incapable, and perhaps only incapable in respect to the treatment proposed, then of course it's appropriate to enter into a discussion and say that you have to share the care decision with the substitute and, "If you have any problem with that, there are remedies."

The question is, should you make it a requirement on every occasion when in many circumstances it would be frankly ludicrous to enter into a discussion with a clearly incapable person who hasn't got the slightest hope of understanding what you're talking about? To tell them they're incapable and then to read them a long printed form and then give them a signed copy of it is just absurd.

There are circumstances where it's clearly in the interest of the patient to be told by their caregiver that

there are circumstances that can be looked at through other routes, such as seeking a review of the decision of incapacity, if they are unhappy, but if they're content with their family member giving consent, why raise the issue? If there's no issue on the part of the incapable person that they're unhappy with the decision of the substitute giving treatment decisions, why raise it?

But I would certainly agree that if the patient is capable of understanding and is expressing any evidence of dissatisfaction with the involvement of the substitute, then the physician or the caregiver has an obligation to discuss the options of appeal to the consent board with the patient. We will certainly advise doctors of that.

0920

**Mrs Helen Johns (Huron):** Thank you very much for your presentation. We appreciate it and we will certainly be looking at it a number of times over the next two or three weeks.

We really need to explore more closely what the health practitioner is going to do in the case where the person is incapable, at a specific moment, of making a decision. Yesterday both the minister and Mrs Caplan, and I believe Mrs Boyd also, talked about we have to ensure that the person gets the best advice, has the best information so that he knows (a) that he's being considered incompetent or (b) that the process is going forward.

We've talked a lot about legislating some way of ensuring the people have advice. We'd like to hear, if we didn't legislate, what you would be prepared to do from the standpoint of guidelines ensuring that the people who fall under your college would be following a process to ensure that the people of Ontario are getting the best rights and therefore the best access to quality health care.

**Dr Gordon:** I can understand that concern very clearly. We feel it is incumbent upon us to assist our professional members to know what the legislation entails and to understand the patient's rights. We have had a booklet of informed consent which touches on this published long before this legislation came in. We put together, with the OMA, this handbook which we sent out to all our members at considerable cost, I have to say, to try and explain the legislation that came into effect last April. We do feel it is important our members understand that the patient has a right to a second opinion if he is being called incapable.

The rights adviser on incapacity, as you know, is not going to advise the patient on treatment; it's only on whether or not they are capable of making a decision. Certainly there are times when the treating physician should be prepared to say: "I don't think you're capable of making a decision on this issue and I'm going to have to ask someone else to help you make that decision, but if you really disagree with that decision, you have the right to talk to someone." That would be appropriate.

There will be other times when it is clearly inappropriate for the physician to try and explain that to the person involved, who really is more concerned about what the treatment's going to be than whether or not they can decide to have it.

It seems to me it puts us right back where we are if we have it legislated that they must read rights. Have you ever read this to anybody? It's something you should all



experience, actually. If you have to read them their rights and sign it and give it to them when you feel they really aren't capable of deciding whether they should have some little bit of treatment, it seems very hard to do.

**Mrs Johns:** Will the CPSO be prepared then to put in guidelines that would lead a professional to have to say specific things, doctors, let's say, in your particular case?

**Dr Gordon:** We certainly are prepared to produce very firm and clear guidelines for our members. I'm not quite sure what you mean by "would have to in every case" because as I've tried to point out, it may not have any application in some cases.

**Mr Frank Klees (York-Mackenzie):** I'd like to not belabour this point but certainly follow up on it for further clarification. We all understand that the scenario you've described to us is cumbersome and obviously unworkable. I don't think any of us have a problem with not requiring you to read someone their rights and get into a long-drawn-out bureaucratic exercise.

What I'd like to pursue is the issue of disclosure, and I think you agree there should be disclosure to people who are about to receive a medical procedure. Would you have any problem if the law at least required that a form of disclosure take place, leaving the details of how that is done to the medical practitioner and allowing your college to develop some guidelines around this issue as to the most appropriate way of disclosure?

My concern is that we're here representing the people of this province who look to us to ensure that their rights are protected, to ensure that they have full disclosure in this matter, and perhaps it would be appropriate for legislation to at least require that the caregiver provide disclosure, leaving the details to you. I'd like to get your comments on that.

**The Chair:** Unfortunately, Mr Klees, there is not ample time to get the answer. We're going to have to move to the opposition.

**Mrs Elinor Caplan (Oriole):** It is a good question and I'm going to follow on that, so perhaps you could answer us both. I appreciate your brief, and I spoke in the House about my own concerns of the bureaucratic nature of the reading, the Mirandizing; absolutely ridiculous. But I am concerned that this legislation removes any obligation on an evaluator, which could be anyone under the Regulated Health Professions Act, anyone under the Mental Health Act or anyone under the long-term-care legislation, to let someone know when there's been a finding of incapacity. For those people who are so severely disabled, it's obvious we would all say, "Well, that's understandable," but there's a very fine line between those who are severely and continuously incapable and those who perhaps go in and out of incapacity. Those are the difficult ones.

My question would be, we understand that all the doctors and others in the province have a responsibility to seek consent from someone who is capable. That's understood. I'd like to know what procedures, standards, protocols you have in place now for the determination of, has someone given consent appropriately? That's one. On the other side, where someone is deemed incapable, do you believe that if they have not informed them of their

incapacity and told them of their right to appeal, that should be considered professional misconduct?

**Dr Gordon:** Absolutely not. I think we should make it very clear that I do not feel this should be done by regulation. I think it can be done very well by guidelines. I would like to make it very clear, perhaps referring to Mr Klees, that when you talk about disclosure, I assume this is a legal term; it's not something that's used very much in the medical profession. We are not disclosing or talking about the treatment; we are talking about whether or not the person is capable of consenting to the treatment. Whether that responsibility should lie with the practitioner, whether it should lie with the substitute decision-maker, is going to vary from place to place.

It needs to have the latitude of being outside regulations. We can produce very strong guidelines for our members on this topic. We produced very strong guidelines for them out of the last legislation, which was very difficult to do, I think we could do it again with a much more useful piece of legislation from a medical care point of view.

**Mrs Caplan:** The concern I have is that as self-regulating professions, unless the government is clear about how strongly it feels that people have a right to be informed when they are deemed incapable and that there is an obligation they be given information about their right to appeal—my question is this: Unless the government says it clearly—they've said it clearly under the Mental Health Act. Under the Mental Health Act, if someone is deemed incapable, by law they must be told of their right to appeal and they must also be told and handed the form of their incapacity. Public guardian and trustee the same thing; under this legislation, there is an obligation that the public guardian and trustee's office must inform someone of the guardianship and give them the forms to appeal.

0930

Why shouldn't that be for anyone who can make a finding of incapacity? What's different about providers who are not under the Mental Health Act or are not subject to the public guardian and trustee? Why are other providers different?

**Dr Dixon:** I think you've already stated that in circumstances when the patient is so incapable, it makes no sense. No one would disagree that there's no sense whatsoever in trying to communicate the right to an individual who is completely incapable and the law has already provided for a substitute to act on his behalf. On the other end of the spectrum are the patients who are marginally incapable but have a very stable relationship with their family and are giving every evidence that they are content with having their family, which is legally entitled and required to act on their behalf.

Why then intrude in this relationship and say, "First of all, as a caregiver, I have to tell you that you are incapable, and secondly, that you have the right to challenge that finding of incapacity," if there is no issue? If there is an issue, then I completely agree that there should be a responsibility on the caregiver to make that right known to the patient. But surely there has to be some exercise of professional discretion in this area. The doctor-patient relationship is founded on trust. The present act tries to



get between the caregiver and the patient and the family. I think we have to give some recognition to the professional responsibility of the caregiver to act responsibly and appropriately in situations where it's indicated.

**The Chair:** On that note, doctors, I thank you for attending and for your presentation. Our time is up and we will move to the next witness.

LINDA BOHNEN

**The Chair:** Our next witness is Ms Bohnen from the law firm of Thomson Miller.

**Mr Tony Clement (Brampton South):** The other way around.

**The Chair:** Miller Thomson, sorry. You're right. It used to be Thomson. Welcome. We have one half-hour for your presentation, including all questions.

**Ms Linda Bohnen:** My name is Linda Bohnen. I'm a health law lawyer in Toronto. I was executive director of the Task Force on the Implementation of Midwifery in Ontario and a member of the Health Professions Legislation Review. For several years I worked at the Ministry of Health, developing and drafting the Regulated Health Professions Act. In my private practice I now give advice to many colleges, professional associations, practitioners and hospitals. I'm not here to represent any of them but rather to give you my own views about Bill 19, focusing on the proposed Health Care Consent Act.

The Health Care Consent Act is a considerable improvement over the Consent to Treatment Act. My experience with the Consent to Treatment Act includes helping to write a detailed manual about it for hospitals, and I have given seminars about it to health professionals. I can tell you from personal experience that the Consent to Treatment Act has been very difficult to teach. Many health practitioners are simply bewildered by it. In my view, the fact that it is so complex has been a very real impediment to its being implemented.

The drafters of the Health Care Consent Act should be congratulated for writing a clearer and simpler act. It's evident that Ministry of Health staff have listened to the criticisms of the Consent to Treatment Act, and I think they've tried very hard to balance competing points of view.

Now, perfection is an impossibility, and it's quite possible that the Health Care Consent Act is as good a piece of legislation in this area as it's possible to achieve. But there are two features of the act that I would like to comment on.

The first is consent for what I call "non-treatment." As I'm sure you know, one of the primary purposes of the consent act is to fill in a gap in the common law. The common law does not give any authority for next of kin to act as substitute decision-makers for individuals, except for children, where they are incapable of making their own treatment decisions. In practice and of necessity, physicians and other health professionals do turn to family members for consent decisions, but this practice has had no official legal sanction prior to the Consent to Treatment Act. That act remedied this by providing a prioritized list or hierarchy of substitute decision-makers, and this list, with some drafting improvements, has been

carried over into the Health Care Consent Act. Under both acts, a substitute decision-maker does have legal authority to make treatment decisions for an incapable person.

However, the authority given to substitute decision-makers only extends to things covered by the word "treatment." Those acts except some things from the definition of treatment. This was done primarily in order to make the obligations in the act inapplicable to commonplace, low-risk acts and procedures. In the Health Care Consent Act, this includes treatments that, in the circumstances, pose little or no risk of harm. At first blush, this seems to be extremely sensible. After all, if a treatment poses little or no risk of harm, then a person would probably have no concerns about the treatment and would readily consent to it.

But there will be a real problem if an incapable person does refuse consent. A capable person is completely entitled to refuse consent to a treatment, no matter how low-risk or no-risk it may be. If the health practitioner ignores the person's refusal and performs the treatment anyway, he or she will be committing a battery. But what if an incapable person refuses consent to a low-risk or no-risk treatment? Because it is not covered by the definition of treatment in the act, the act doesn't apply and a substitute decision-maker has no legal authority to give consent on the incapable person's behalf. I'd like to give you an example.

My example is that of a Pap test, which is part of a routine pelvic examination. It's a very low-risk procedure with proven value in detecting cervical cancer at a very early stage. Yet, a pelvic examination is an invasion of privacy and an assault on one's dignity, however small an assault that may be. I can certainly envisage an incapable woman objecting to a pelvic examination. Because of the exception in the definition of treatment for low-risk treatments, there will be no way of obtaining a valid consent to a pelvic examination except for going to court for the appointment of a guardian under the Substitute Decisions Act. Yet, this is precisely the problem the legislation was intended to overcome.

The Health Care Consent Act does try to overcome this problem in relation to low-risk or no-risk treatments in care facilities. I think that's the primary motivation for part IV of the Health Care Consent Act. Under part IV, you can opt into the act in connection with personal assistance plans, but I think there's a simpler solution and one which could apply everywhere: in hospitals, care facilities, practitioners' offices, patients' homes.

The solution I suggest is to make it possible to opt into the act for acts and procedures excepted from treatment, such as treatments that have little or no risk. For example, suppose that a woman assessed as incapable does object to a pelvic examination and a Pap test. Since these are low-risk procedures, the act does not automatically apply to them. A provision could be added to the act to make it apply on an optional basis. The physician would inform the woman that she cannot make her own treatment decisions because she is incapable, and that consent will be requested or perhaps has been obtained from her substitute decision-maker. The woman would also be told of her right to object to the finding of



incapacity to the Consent and Capacity Review Board. The examination would be postponed for a time period set out in the act to give her an opportunity to appeal to the board. If the woman did not object to the examination or to being found to be incapable, then the physician would simply proceed with the examination and a very valuable form of preventive health care would be carried out.

I think this solution provides a balance between protecting a woman's right to autonomy and not throwing up unreasonable obstacles to low-risk health care. If substitute decision-makers can be authorized to make decisions about treatments with risks, then surely they should be permitted to make decisions about treatments without any risks. This solution will safeguard the practitioner too, because if the patient objects and there is no consent, performing the examination would be a battery. The practitioner could be sued or a complaint could be made about him or her to their college. With the addition of this provision, it might even be possible to eliminate part IV of the Health Care Consent Act, since many of the activities falling within the definition of "personal assistance activities" are in fact treatments that have very few or no risks.

0940

I'd now like to speak to rights notification, an issue that I know concerns you greatly.

One of the significant differences between the Consent to Treatment Act and the Health Care Consent Act, of course, is that provisions requiring practitioners to inform patients that they are incapable and that they may appeal the finding have been removed. Many health professionals have objected to the provisions in the Consent to Treatment Act. I don't believe that they have objected because they don't want patients to be aware of their rights; I think it's because they have found it too difficult to figure out when notification had to be given, and because giving the notification often seems like a useless formality or hurtful to the patient.

I support the removal of the provisions as they existed in the Consent to Treatment Act because mandatory provisions are not the most effective way of getting rights information into the hands of patients when they need the information. I start with the observation that most people who are ill want to be treated for their illness. The legislation makes provision for people to express wishes about future health care through such devices as living wills and advance directives. I think it's reasonable to think that a person who does not want a particular kind of treatment or any kind of treatment at all will express a wish to this effect. Based on these observations, surely it's reasonable to permit health professionals to exercise judgement about notifying incapable patients. It could be expected that they would do so if the patient objected to the treatment or to having their decisions made by a substitute decision-maker.

I'm aware of the fact that during the second reading debate of the bill, Mrs Caplan indicated that her party would be proposing an amendment to require the colleges to issue practice guidelines or standards on rights notification. This could take the form of an amendment to the Regulated Health Professions Act or the Health Care

Consent Act. I'm going to suggest that an amendment of this type is not necessary and not desirable.

It's not necessary because a law does not need to be passed to induce health practitioners to give rights notification when it is called for. Bear in mind that in some professions it will almost never be necessary because of the nature of their work and their clientele. Members of other professions, such as physicians, regularly make judgements about capacity. My experience with the colleges suggests that they will discuss rights notification issues with their members when they provide information to them about the Health Care Consent Act generally.

In my view, a statutory requirement is too heavy-handed an approach, one more likely to raise hackles with colleges and health professionals than to exert a positive influence on their behaviour. After all, you either believe in self-governance or you don't. Every college has already defined it as professional misconduct for a professional to treat a patient without obtaining an informed consent.

Secondly, professional associations also play an important role in standard-setting and in educating professionals about developments in the law.

Thirdly, I know from personal experience that the Ontario Hospital Association and individual hospitals have expended considerable resources on developing ways to ensure that hospital staff implement changes in consent law.

If you still believe that the government needs a way of requiring a college to take action, then I think that means already exists. The Minister of Health has the power, under section 5 of the Regulated Health Professions Act, to require a college to take action that the minister considers appropriate. In addition, if a college refuses to make a regulation after being requested to do so, the cabinet can make the regulation in its stead. This has been very rarely exercised, but the power does exist.

In conclusion, I'd like you to consider that for a consent act to be effective, the practitioners who will be applying it must buy into it. That can be extremely frustrating I think for both legislators and people like me who sometimes draft laws because we think that, darn it, if we write it and if we pass it, they ought to apply it. But life is more complicated than that, and buy-in is necessary for them to invest the necessary time and effort to change their habits and practices.

Eventually the Health Care Consent Act will become ingrained, new habits will form and the culture of health care will change. The Health Care Consent Act, in my view, is more likely than the Consent to Treatment Act to achieve positive change in the culture of health care, for reasons I've already given. But change takes time, and so my final suggestion is to give the Health Care Consent Act sufficient time to work and, please, let's not have a third consent act for at least a few years.

Thank you for your attention. I'd be happy to answer any questions you have.

**Mr David Tilson (Dufferin-Peel):** I must say I'm tempted to pass when you say it's as good a piece of legislation as one could get, but I do have one concern—actually, I would have liked to ask it of the College of



Physicians and Surgeons—and that has to do with the rules for determining capacity and, in your experience as a solicitor and also working for the ministry, if you could give us your comments. I guess there are different ways of doing it, and I think you may have touched on it in your comments talking about the powers of cabinet. Obviously, one can set up these rules in regulation, one can ask or hope that the College of Physicians and Surgeons will do it, or you can do something in the act. Can you tell us what your thoughts are on that issue?

**Ms Bohnen:** I think when you consider the rules or guidelines for determining capacity, you have to start from the point that in this legislation, capacity is specific to a particular treatment at a particular time. It's not like the global concept of incapacity that lends itself to uniform criteria such as we have under the Substitute Decisions Act. We're talking about whether Jane Doe at a particular moment is capable of giving an informed consent to a particular treatment. So it's more of a floating concept.

There were very detailed regulations outlining the intellectual process, if I can put it like that, under the Consent to Treatment Act. I had a problem with that because I think it differed from the concept that was embedded in the act itself. My personal preference would be that we not try to spell out in detail a process like that, but have it clearly in the law, as it is, that for a consent to be valid, it's got to be obtained from a capable person, and only the capable person can give the informed consent. Given the possibility of complaints to the college and civil actions for damages against health professionals, I think that physicians anyway have sufficient motivation to make sure that they do it right.

**Mr Tilson:** I guess, as you say, the real difficulty is that there are different people, whether they be children or whether they be seniors or people of different stages or different health problems.

**Ms Bohnen:** The health problems change, the age and stage of life change, and the treatments change. The measure in capacity to consent to something quite simple is very different from assessing capacity to determine, for example, some complicated form of treatment for cancer, whether the person has the capacity to give an informed consent about that. It's extremely variable.

**Mr Tilson:** In short, you support the initiative of—

**Ms Bohnen:** Yes, I support the initiatives, and I think that although we may be uncomfortable with it, we don't have much choice other than to entrust regulated health professionals to use their best judgement in making these assessments.

**Mrs Caplan:** I like debating with you, Linda.

**Ms Bohnen:** Oh, oh.

**Mrs Caplan:** I agree with you that there are a lot of improvements in this legislation. However, I have a couple of concerns, and that is the recent case that we just heard in Alberta where a woman was sterilized against her will. As I read this bill, it is possible in Ontario. No one would have to tell her she was deemed incapable; no one would have to tell her where she could apply. She would have been incapable and that would be done, and this bill would permit that.

The second point I would make, and this is in the form of a question, is that we've heard from the College of

Physicians and Surgeons that they believe it is professional misconduct if you do a procedure without consent from a capable person, but we just heard that they do not believe it is misconduct if you do not inform someone that you have found them incapable and have not informed them of their right to appeal, and done the procedure.

0950

**Ms Bohnen:** On the sterilization point, I'll just remind you that the act does not apply to sterilization that is not medically necessary for the protection of the person's health, because I think there is an appreciation that sterilization is a particularly sensitive and difficult issue.

With respect, though, to the broader point, what we all want to do is make sure that when it is appropriate, a patient who has been found to be incapable is told of that finding and is told of the right to challenge it. The only issue is, how are we going to achieve it?

Frankly, I'm dubious that simply adding a provision to the RHPA or the Health Care Consent Act saying to the colleges, "Thou shalt issue practice guidelines," or make a standard requiring physicians or whoever, requiring health professionals, to give this information in appropriate cases—frankly, I don't know if it's worth the ink or the paper it's written on. What we have to do is encourage the colleges, encourage health professionals to use their heads, to remember that they are there to act in the best interests of the patients, and give them the education and the resources to do just that in situations where they and everyone else would agree it ought to be done.

**Mrs Caplan:** Linda, why is it appropriate under the Mental Health Act to require that a person be told that they have been deemed incapable and be told of their right to, I think it is, make a submission to the board or appeal to the board. Similarly, in the case of the public guardian and trustee, we are very comfortable saying to them, "You have to hand the person the form of incapacity and tell them of their right to appeal." Why in those two cases does that work, but a requirement or a request that the colleges set up similar procedures—why do you think that should raise hackles? If medical practitioners, particularly psychiatrists and others, are already doing it under the Mental Health Act, why are only those people given that protection and those rights?

**Ms Bohnen:** I think that in relation to patients in the psychiatric system under the Mental Health Act, we do recognize that psychiatric illness and committal, involuntary committal, raises issues of particular sensitivity, and therefore we've traditionally dealt with them with greater protection for the civil liberties of individuals. In relation to guardianship orders and the public guardian and trustee's responsibilities, I think there are two differences. One, it's a government office. Secondly, a guardianship order has a much more pervasive effect over someone's life than a discrete decision that in relation to one treatment at one time, you are incapable.

I don't disagree with you at all that colleges ought to provide guidance to their members about this issue. Where I differ with you, though, is in whether writing a section in an act is the way to achieve that. I think we're fooling ourselves if we think that's going to achieve the result that we want.

**Mr Rosario Marchese (Fort York):** This is the same point I wanted to pursue, because I have some trouble with the view you're presenting. On the whole you say that the existing act was too onerous in terms of what it obliges doctors to do. On the other hand, you say no guidelines are necessary because you say that "Members of other professions, such as physicians, regularly make judgements about capacity."

From your point of view, it seems that doctors will always act wisely and will do the right thing, and I appreciate that and we think that's the case most of time. My concern is, how do you balance the rights, of course, of the profession with the rights of individuals? What you're saying, if I understand you correctly, is that the rights of the individual are protected because the medical profession will always act on behalf of the patient because that's the nature of the profession.

**Ms Bohnen:** Firstly, there were two problems with the Consent to Treatment Act. One of them is that the rights notification provisions were too absolute and unrefined. The other problem was, frankly, speaking as a lawyer who practises health law, they were too hard to figure out most of the time. It was very, very complicated, so we needed to simplify it. I agree with you 100% that there need to be guidelines and that health professionals need to be coached, educated and encouraged to provide rights notification and information. My only quarrel is that I don't think writing a section in this legislation is the way to produce that result. I think there are better, more effective ways of achieving that result.

**Mr Marchese:** To be clear, on the issue of guidelines, you're saying there should be, or there shouldn't be, or there should be guidelines but not written into the act?

**Ms Bohnen:** I think there should be guidelines, that colleges should provide them, and that neither the guidelines nor the legal requirement to do it needs to be written into the act.

**Mr Marchese:** Right, because the act obviously doesn't say, "We shall educate the profession" in some way or other. What you're saying is the profession should do it and we should encourage them to do that, but there's no obligation, no control, no regulation.

**Ms Bohnen:** No. I also pointed out that if they fail to do so, the minister has powers under the Regulated Health Professions Act to require the college to do so, so that if the College of Physicians and Surgeons, or any other college for whom the issue is relevant—it's not relevant for some. Dental technologists don't even have any contact with patients. But if they refuse to do so, then the minister can access the powers the minister already has.

**Mr Marchese:** What we should do then is wait for a period of time, however long that is, wait for something that happens that will indicate to the government that perhaps we have gone wrong and we should do something, and then see what happens, that sort of thing?

**Ms Bohnen:** You could do that, but you could also do what Frances Lankin did as Minister of Health in relation to patient relations program vis-à-vis sexual abuse. She wrote to each college—she had no legal authority at the time to do so, except in the RHPA—and said: "I would like you to do this. It's in the public interest. Would you

please develop a plan and let me know what your plan is." That worked.

I know my time is up. I'd just make a plea: Don't forget the issue of making it possible to use the act for stuff that's not a treatment. There's an inquest going on right now that's relevant to that in this city. Thank you.

**The Chair:** Thank you, Ms Bohnen.

BRENDA SINGER

**The Chair:** Our next witness is Ms Singer. The committee should have received the written submission dated February 6, 1996. You may proceed.

**Mrs Brenda Singer:** Thank you. I'm here today as the mother of a severely disabled young man whose life was profoundly affected by Bills 108 and 109. My son Brian now lives at Southwestern Regional Centre in Blenheim and receives a controversial treatment called faradic stimulation, or contingent electric shock, which is used as aversive conditioning to prevent him from severely beating himself. This treatment was prohibited in Bills 108 and 109, and my primary purpose for coming here today is to commend you for inclusion of electric shock as a legitimate and necessary treatment. I believe that Brian's story will convince you that you have made a wise decision. The issue became a life-and-death issue for my son, and I feel it is important to give you some background. If you'd like to see who I'm talking about, if you turn to appendix A you can see what my son Brian looks like. I'll be showing you a video later.

When others with different views who are not directly involved in the issue attempt to reverse your decision, you will have the facts from one of the only two families in the province affected by this issue and by this legislation.

I'm a mom and I've come here really to talk to you from my heart. As I have faced the systems, I have had to become knowledgeable, and that's why I've sort of accumulated some documentation for you to read if in these proceedings you have the opportunity to do so.

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Brian is a 27-year-old developmentally disabled young man with a 20-year history of self-injurious behaviour. He has been tested as profoundly disabled. He functions at the level of a two-year-old with no verbal skills. He demonstrates autistic behaviour. He is able to dress himself with assistance, eat independently, ride a tricycle and swim. He was born in Montreal in 1968. He's my eldest son and, although we were not aware of it at the time, he had trouble breathing for the first six minutes of his life.

He went to a school in Montreal, where we come from, for developmentally handicapped children and lived at home. Brian's self-injurious behaviour began when he was approximately seven years old. In his early years he was assessed at various hospitals and received a range of behavioural approaches and all kinds of medication trials. The only successful treatment at that time, when he was very, very young, was the use of two elbow splints which were designed by a physiotherapist friend of mine. He wore them to straighten his elbows so that he couldn't bend his elbows and hit his face.



Brian lived at home and attended a school in Montreal until he was 10 years old. In 1978 our family moved to Ottawa and our life together was torn apart. Brian went to a school for developmentally disabled children, from which he was sent home after only one day because they couldn't manage his behaviour. We were told that he was our responsibility, as there was no school that could accommodate his needs. I was at home at that time with his infant sister and younger brother.

The Ottawa school board convened a placement meeting and told us that our only alternative at the time was for respite care during that summer at Rideau Regional Centre. It was really, indeed, with broken hearts that we drove our son to Rideau for the summer, hoping to find an alternative. A few months later we found a group home in Ottawa where people who lived there could go to a day program. He lived in the setting for a year. However, the staff wasn't able to handle his self-injury and one time he spent a week at the Children's Hospital in Ottawa because he was put in a time-out room and he was in the hospital with a black-and-blue face. Finally, the group home staff concluded that he required one-to-one staff ratio. They couldn't deal with his needs and he returned to Rideau Regional Centre as there were no other alternatives for our family.

In September 1978—Brian was then 10 years old—he was admitted to Rideau, where he became a resident for the next seven years. During those seven years he would have periods of extreme self-injurious behaviour where being in a straitjacket and a helmet became routine, and there would be intervening periods of some stable behaviour. Many different types of medication were tried during his stay at Rideau. I've listed them all here; I won't go into them. Many of the medications were entirely experimental, but we willingly agreed to these medications, hoping to find relief for our son.

In 1978, while Brian was a resident at Rideau, our family moved to Toronto but continued to visit him regularly. We advocated on his behalf to find a suitable community setting for him to be closer to our home. In 1982, he was admitted to the Lawson Residence operated by the Metropolitan Toronto Association for Community Living. However, unfortunately, on the first day we received a call from their staff saying that they couldn't handle Brian, to please remove him immediately. He did not react well to change, was biting staff and other residents, and was considered not behaviourally compliant. We brought him back to Rideau after the failed community experience.

The staff of Rideau became increasingly concerned about their inability and lack of expertise to cope with Brian and recommended Dr Barrera's program at Southwestern Regional Centre. Brian was crying constantly and was extremely self-injurious. Brian was actually in a straitjacket for the last 18 months of his residency at Rideau. At one point there, a staff doctor recommended that we amputate Brian's ears as a solution. It wasn't their lack of care but their lack of knowledge that became the problem. So his transfer to Southwestern Regional Centre, to our family and to Brian, was a lifesaving measure.

Brian was admitted to Southwestern Regional in October 1986, when he was 18 years old. When Brian arrived at Southwestern, as I mentioned, he was wearing the straitjacket to keep him from beating himself; he was also wearing a football helmet to prevent him from pounding his ears with his knees. He arrived at Southwestern with a cracked bone in his arm despite all this apparatus that he was wrapped in and the heavy doses of medication. Also, his fingers were becoming atrophied because they weren't used for 18 months.

At this point it is essential, from my perspective, for you to see what Brian was like when he arrived at Southwestern and how, within a matter of hours, he was weaned from the straitjacket and helmet and began to regain his life. I have to tell you, and you can understand, that for me as a mother it's absolutely heart-wrenching for me to listen to and watch this footage, but I think it's more important, and I must put aside my feelings for the moment, so that you can develop some understanding of what the issue is.

It's very brief; this section of tape is no more than five minutes. A lot of people talk about faradic stimulation and don't understand exactly what a lifesaving measure it is. What you're going to see now is Brian for the first time in 18 months having the straitjacket taken away from him. This is information that we got from the ward. We were entirely aware of what they were doing. We sort of saw it all. My husband this past weekend just made a little synopsis so you'd have an idea, because in the abstract it's very hard to talk about something so difficult.

This is the very first day in 1986, his very, very first treatment, where he's being exposed to faradic stimulation. He's screaming because he was comforted by the straitjacket and the helmet to prevent him from hurting himself, and he doesn't want to give them up because he's afraid he'll hurt himself. That's why he's crying.

This shows how difficult it was for him to eat before he got the treatment, because they had to take him out of the straitjacket, lift up the helmet and try to feed him while he was trying to beat himself at the same time. So this predates the first application of faradic stimulation. It was very, very, very difficult for the staff, for him to be able to eat, which they wanted him to do, of course. Now Brian is getting used to being without the straitjacket. He would try to take his knees and hit his ears with his knees; that's what he's doing there. It gets better in a minute, I promise you.

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This is very lovely. Brian is riding a tricycle with his worker. It's an adult-sized tricycle and he's having a wonderful time and he's a happy boy here.

You're going to see another shot. The treatment in 1994 was taken away from Brian in anticipation of the legislation. You're going to see in a few minutes a terrible shot of what his ears looked like. But he remained that happy boy from 1986 until the treatment was taken away from him in 1994, and now he's okay again.

He is with his case manager now. He's back on treatment and he's feeding a shredding machine and he seems to be very happy. My son is extremely affectionate, as you'll soon see. This is a happy picture and this is how he is now.

Prior to the commencement of faradic stimulation, an exhaustive regime of behaviour techniques was used in order to ensure that this treatment was indeed a last-resort treatment. It's important for you to know that there is a very extensive approval and monitoring process of faradic stimulation that makes it a highly regulated treatment procedure in Ontario. There are strict standards and guidelines for its use.

I have provided some documentation in the packages, in appendices B and C. There is a photograph of the clinical equipment that's used and there's a lot of information about faradic stimulation itself and about all the various committee levels it needs to go through before someone is approved for this kind of treatment.

It's important for me to speak about this equipment for a few moments, because you're going to hear, I have no doubt, words during these proceedings—I've just come at the beginning—but you'll hear words such as "barbaric," "torture," or other emotional words to attempt to dissuade you over the course of these meetings.

I want you to know that I did a lot of research before our family made the decision for Brian to get this treatment. We visited Southwestern Regional Centre, we met with Dr Barrera and all his staff. Myself, my husband, my son who is sitting there all tried faradic stimulation. It doesn't have any more effect than it does for a person to walk across a carpet and receive some static.

Brian can accept pain, as you can see—this created by his 500 to 900 hits to his face per day—but for some reason there's an uncomfortable neurological sensation that he cannot tolerate, and that's why it works. We don't quite understand it, but it works. It isn't painful and it's certainly not painful like his self-inflicted injuries. It's not damaging or dangerous at all.

People get faradic stimulation confused with ECT and all kinds of other procedures. All it is is a very, very mild stimulus to the fatty tissue. It's given to a person's leg or to a person's arm, and it generates less current than a pacemaker. I'm sure you know people with pacemakers. There isn't any more risk than that. It doesn't have the side-effects, believe me, that Brian was affected with over the many, many years that he was subjected to all the drug trials.

You'll probably ask, why would parents subject themselves and why would they search so hard for this kind of treatment? First of all, we knew that the procedures were highly regulated and, secondly, we had to be convinced that no stone was left unturned and that this was truly the treatment of last resort.

You were able to see on the video how Brian's quality of life improved immediately. He could ride his tricycle. You saw him swimming. He attended programs. He was really cheerful and happy compared to the Brian prior to the treatment. In 1993 Brian was up to the point where he received only five shocks for the entire year. However, in 1993, in August, in anticipation of the ban on faradic stimulation, the Ministry of Community and Social Services instructed Southwestern to withdraw the treatment.

In January Brian had gone almost four months without the treatment, and by January he started to become self-injurious again. Just within four weeks, Brian went up to

hitting himself 400 times a day, and very soon he was at the 1986 level and everything that had been gained was lost. He was beating his ears, using his knees again to hit his ears. His ears were bleeding internally and externally. I would call and there'd be blood over his pillow. Every single night they would be cleaning him up because of rubbing on his ears. You saw what they looked like. He refused to eat during that period and lost seven pounds in just two weeks. He was really at the brink of disaster.

I did what I could as a mother. I wrote, I talked, I pleaded with ministry personnel, and in April 1994 I met with the Minister of Community and Social Services, Mr Silipo, and told him about my son's plight and that Brian was right back to 1986 levels. Shortly after that, in May, in recognition of his regression and its possible consequences, because we were really afraid of brain damage and deafness, the ministry allowed the temporary return of faradic stimulation.

#### 1020

To give you some insight into the efforts that were made at Southwestern Regional, I can tell you that every expert was called in. There were medication trials from Dr Hinton, a paediatric neurologist; Dr Ben Goldberg, consultant from the University of Western Ontario; a Dr Kastner; a Dr Herb Lovett of Boston; Dr Dana Henning of Pennsylvania. A full spectrum of new technologies was tried, including gentle teaching and even acupuncture over a course of months. Additionally, newer non-tranquillizing medications such as Buspar and naltrexone were used. In addition to chemical restraint, there was physical restraint, four-point bed restraint and wrist cuffs.

Currently you've seen how Brian functions, and I want you to know that monumental efforts have been made such as the ones I've cited on the part of the treatment staff at Southwestern, and the only technique that has afforded Brian a decent quality of life has been the use of faradic stimulation.

My husband and I, and Brian's brother, sister, grandparents and family who know and love him, want him to be happy and safe. Perhaps one day there will be a proven effective treatment that will assure him of the same quality of life that he has or even a better one. We want our son to be happy and we really thank you for what you've done with the legislation, because you've looked at the grey side of issues, and we certainly know that life is full of grey.

At this time there are only two families—that's important for you to know—in the entire province that were affected by that legislation, and we're happy that you've heard us. We're pleased that our new government has come to the determination that faradic stimulation may be used as a treatment.

We believe that it is our son's constitutional right to have this treatment as much as it is the right of any person who is physically ill to have any other intrusive treatment, such as chemotherapy, insulin treatment, surgery, anything that's just become part of life today that people need. We can't take this away unless there is another safety net there for Brian, and there wasn't a safety net when it was taken away in 1994.

I would like to thank you on behalf of myself and my family for the opportunity to bring this issue to you and, most importantly, thank you from Brian.



**Mrs Caplan:** We've met before, and I think, unfortunately, you've had to go through a situation where the only appeal was actually to the minister. While this legislation removes the absolute ban, my concern is that it doesn't have the accountability written into it that I think could be there without forcing you to go through all of what you've gone through. When we met, I had said, "Do you mean you can't go to any board?" and the question I have is, would you be comfortable—

**Mrs Singer:** No, I would not be comfortable. A person who is taking insulin doesn't have to go to a board; in fact there's no other medical procedure which is written into the legislation. Writing a medical procedure, a treatment, into the legislation in the first place is unprecedented.

I can understand, in terms of the concern about abuse, why it is written in now, but as long as it says "unless it is a treatment"—we're talking about treatment. We're talking about a huge procedure. There are about five committees that the treatment staff has to go through before it's allowed to be used. Given all the ethical steps and procedures, I think it's a very, very ethical process and the words, "unless it is a treatment," to me guarantee that it will be used safely, because if it's just used arbitrarily, then it's being abused and then it's not a treatment. "Used as a treatment," to me, is the protection.

**Mrs Boyd:** The argument has always been around whether it's a treatment or whether it's a behaviour modification technique, and that has always been the base issue on this matter. I think you will agree that the program at Southwestern has treated a great many more than two people and, in fact, this so-called treatment has not been effective for many of those people. In fact, one of the things we saw when this legislation was pending, they were instructed not to just remove it from people, but to do that work between 1982 and 1995 when the act came into effect. That, unfortunately, wasn't done and you folk suffered as a result.

But the issue is that in the experimentation that's been done, the research that's been done, very few people respond as positively as Brian has to this. The major concern has been, as with many other kinds of aversive treatment—we've seen a recent situation with brain-injured children at Chedoke-McMaster, for example, where aversive behaviour modification treatment appears to be the norm, and the real concern always was to make sure that that intrusive and aversive behaviour modification technique was very much a last resort and very, very much the kind of thing that would only be used when the evidence was very clear that nothing else was going to have the effect. You should know that those in favour of this, other than the parents, certainly are in favour of it in a much broader context than what you're talking about in your particular individual case.

**Mrs Singer:** That hasn't been my experience, Mrs Boyd. The people I have talked to have been in similar situations to mine where it has been a lifesaving measure, and certainly every single step was taken. Brian arrived at Southwestern Regional Centre and was there for several months, even in the condition that he was in, before every single other procedure was tried, before this step was taken, so I have no—

**Mrs Boyd:** I think that's true, but you will admit that of the six people who were having the treatment at the time that it was removed several of them showed no change and did not have the dramatic reversion that your son displayed. So there clearly needs to be some way in which there can be some very clear way to ensure that this is an absolutely necessary medical treatment as opposed to an aversive behaviour modification technique.

**Mrs Singer:** I think there were—Dr Goldberg sat on the committee, and in any treatment it doesn't work with everyone, but people are still allowed to try it. People have mastectomies and it's not always successful, but people still go through that radical procedure. People do die after breast cancer, but some people do survive.

I know, I'm familiar with all of the six people who had faradic stimulation around the same time as Brian. I'm at the ward all the time. I know these people, I know their families and I know that when it was deemed unsuccessful it was withdrawn. It was tried. Sometimes something is effective at one stage in a person's development and it's useful, and then it no longer becomes useful.

I think it does need to be highly regulated, I agree with you, but I think it's a grey issue; I think it can't be a black-and-white issue. The way it's put in the legislation right now is for the few people who need it. I would not like to see it tampered with; I want it to stay exactly the way it is. That's what I'm here to say.

**Mr Tilson:** Thank you for your presentation. I can't believe you haven't had an effect on all of us here today and I look forward to reading in detail your brief. My understanding is that this type of stimulation is not prohibited anywhere else in Canada. Obviously you have become an authority on this topic. Can you tell us about that and perhaps other jurisdictions in the United States?  
1030

**Mrs Singer:** It is allowed in the United States in quite a few jurisdictions, and in all of the settings where it goes on it's highly controlled, as it is here in Ontario. That certainly is my understanding. You will hear from some people who will be coming up to Windsor and who will be able to talk with you about the treatment that's being given in some American settings.

In terms of Canada, I'm not aware at the moment of any jurisdictions and I'm not knowledgeable about the geography of faradic stimulation and the sort of research in terms of other provinces. But I can tell you that just because a province doesn't give it, perhaps for political reasons and all kinds of reasons—because it's very, very sensational. It's not unlike another hot emotional issue like abortion; it seems to really, really sort of spark people. So it doesn't mean that there are not people languishing in institutions who are bound up in strait-jackets and chemically comatose because they're deprived of this treatment. So just because it doesn't exist doesn't mean that it isn't needed. It just might be that for some political reasons it isn't given.

**Mr Tilson:** Thank you very much for coming to us.

**The Chair:** Thank you, Mrs Singer, on behalf of the whole committee. We thank you for the courage to share this experience with us.

**Mrs Singer:** Thank you. It was difficult but worth it.

## PSYCHIATRIC PATIENT ADVOCATE OFFICE

**The Chair:** Next we have the Psychiatric Patient Advocate Office. Gentlemen, identify yourselves for the purpose of Hansard.

**Mr Brock Grant:** My name is Brock Grant. I'm the acting director of the PPAO, and with me is David Giuffrida. He's the legal counsel with the PPAO. You have before you a submission from our office that outlines some 17 issues with respect to the legislation and what our feelings are about it. We'll be pleased to answer any questions you may have with respect to our submission after we take you quickly through it. So I'll turn you over to Mr Giuffrida.

**Mr David Giuffrida:** Good morning. I want to apologize for the length of the submission. It runs 25 pages, and I would have liked to devote equal or I think greater space to talking about all the aspects of the amendments that we think are well considered, thoughtful and will improve the quality of life of people with disabilities in Ontario, and they are numerous.

But I think the time can be used most effectively talking about some of our concerns about the legislation and suggestions that can help ensure that it better balances the state's paternalism, our well-intentioned intervention to protect people from harm, versus the autonomy of the individual, which is also something we cherish in our society.

Given time limitations, I won't be commenting on every part of the brief. Some of the suggestions regard fairly technical matters that may be self-explanatory, and I'll just deal with them in the question period if you have specific concerns about them.

I want to turn first to the Health Care Consent Act. Issue 1 deals with the use of the word "appeal." It's a technical matter that we need not dwell on here, I think.

Issue 2 deals with exclusions from the definition of "treatment." It was heartening to hear Ms Bohnen's presentation to you about this issue, because in it our program raises the same concern, that we understand what the government's goal was in trying not to visit a whole lot of due process on really fairly non-invasive treatments, but, as Ms Bohnen has pointed out, we think that the scheme that has been adopted may miss the mark, and we've suggested another way that may be more responsive.

I'd like to talk about issue 3 on page 4 of the brief. This concerns the removal of all references to rights advisers and the elimination of the requirement that rights advice or notices be given to a person who has been determined to be incapable. I know even in the short time this committee has been considering Bill 19, this has been a subject of significant discussion, and it's an issue of great concern to our program as well. Our program has been providing independent rights advice to people determined to be treatment incapable for a number of years, and we believe that's the gold standard as far as ensuring the autonomy of the individual as far as ensuring that they have an opportunity to relate effectively to a complex system that can do very invasive things to them, perhaps well-intentioned but none the less very invasive and perhaps irreversible.

We believe that, at a minimum, an obligation ought to appear in legislation obliging health care professionals who determine someone to be incapable to inform the patient that they've been determined incapable and to tell them about their right to apply to the board. If it's not in legislation, will it happen? There have been a number of questions directed to that. I think the answer is clearly it won't happen, either at all or with any consistency. Is it already a standard of the medical profession, for example, that you must tell people about their right to go to the board and tell them they've been found to be incapable? No, it's not; it's a matter for discretion.

The College of Physicians and Surgeons representatives this morning were asked that question: Do you consider it to be professional misconduct? "No, we don't." They don't put it in the same category as, for example, informed consent. I think what the medical profession regards as the knowledge the patient needs to know has consistently been less than what the patient wants to hear. The Supreme Court of Canada, in the early 1980s, when they were making law about informed consent, said the standard is not what the reasonable physician thinks the patient should know. The standard is what the reasonable patient would want to hear. I don't think we can leave it, for example, to the medical profession and 22 other professions to internally decide what they think the patient ought to hear or whether they are too confused to get that information. I think we've had a clear indication this morning that this would not be effective.

I note too, on page 5, several examples where the stakes are much lower. Perhaps it's the licence of a door-to-door broom salesperson. The registrar or the director is not given discretion to decide whether or not to tell the person about their right to appeal, to decide whether they seem unhappy or happy with the decision and exercise their discretion. The registrar is presumably a reasonable professional person. We don't leave it to them. We've put it in the statute. When the stakes are so much higher, when the stakes are as high, as I point out, as a possible amputation, and you tell the person maybe they're in for gall bladder surgery—because the woman in Alberta who just won a three-quarter-million-dollar judgement wasn't told that her fallopian tubes were going to be removed. She was told by a physician, who we must accept was in a relationship of trust with her, and 2,800 other people sterilized back then, that she was in for some other surgery.

Nothing in the Health Care Consent Act would require a doctor today to give a patient any more information. I'm not talking about eugenics in 1995—that's off the table—but any other invasive, irreversible thing. You can lie to the patient, you can tell them it's something else—after all, you've determined them to be incapable—as long as you get consent from the substitute. Does the profession operate to a higher standard? We've heard this morning, no, they don't feel they routinely need to. It's a matter of discretion.

Issue 5 on page 8: Use of cattle prods on incapable people to be permitted. If we're going to contemplate a case in which the use of faradic stimulation for aversive conditioning is to be accepted, I think Mrs Singer pres-



ented the most compelling circumstances we can imagine. It is because such circumstances do exist—and it is a controversial treatment. There are people who assert that gentle teaching techniques using exclusively positive reinforcement can uniformly work. But there is not yet a consensus in Ontario that they will uniformly work, and Mrs Singer made a powerful presentation about what may be one of the few exceptions.

That's why we think the better road may be, rather than an absolute ban at one extreme, or, at the other extreme, treating a punishment technique like a flu shot, that there be standards and accountability. I'm pleased to hear her describe the kind of standards that there are I assume in Ministry of Community and Social Services facilities. Nothing in this legislation would confine the use of cattle prods to Comsoc facilities. It could be anywhere. I don't know if these cattle prods got less painful in the last 10 years, but when I got zapped it hurt like the dickens. It has to for it to deter you from the behaviour they want you to stop doing. It's punishment.

On the subject of punishment, the suggestions that we make about aversive conditioning would probably be prudent to apply not just to cattle prods, but to other kinds of aversive conditioning. It's not part of our presentation to screen this video, but *The 5th Estate*, as reference has been made, broadcast a bit of journalism dealing with the use of arms being pulled behind the back until the person cries out in pain and verbal abuse as aversive conditioning. To keep someone from poking their eyes and ears out, if you balance the pros and cons, you might say that's the lesser evil. How about to make a 10-year-old eat his mashed potatoes? Because that's in here as well. If we think that's okay, then we'll treat aversive conditioning like a flu shot. If we don't think that's okay, I think we need to impose some standards so that a PhD in physical education cannot induce nurses to jerk people's hands behind their back. If we're troubled by that, then we need standards about it.

1040

I'd like to turn to page 11, the definition of "rights adviser" under the Mental Health Act. As I said before, the gold standard for ensuring that patients are told their rights is an independent rights adviser. That service has been delivered by our programs since 1986 or 1987. It's been delivered by lawyers sent by legal aid area offices for a number of years. And since April 3, people hired by and authorized by the Advocacy Commission have been giving rights advice.

The new definition of rights adviser would allow someone to be designated by the administrator of a hospital to be a rights adviser, and that's a clear conflict of interest. You've heard this morning from the College of Physicians and Surgeons just how uneasy it makes health professionals to give people blunt information about their rights. They want it to be a matter of discretion.

I think the relationship between a rights adviser and the person they're giving advice to is one of a strong fiduciary relationship. I think if you oblige a hospital staff member, who may spend most of their time as part of a treatment team, to try to work to that standard of an independent rights adviser, it puts them in a conflict of interest and may expose them and the hospital to legal

liability if they don't do it to an acceptable standard. I think it's preferable to ensure the integrity of rights advice and, where the legislation provides for rights advice, ensure that it's independent of health providers.

At the bottom of page 13 we begin to discuss amendments regarding the Substitute Decisions Act. Again, the theme again we're trying to develop is one of balance, and it's not about demonizing all health care providers or demonizing all family members, but we can't canonize them all either. Unless we're born in a test tube, we're all somebody's family, and we can't all be angels. Some of us are jerks.

There is a police constable, Dianne MacInnis, Metropolitan Toronto Police, who this morning faxed me statistics about the elder abuse cases that come across her desk in her department. I haven't circulated copies for everybody. I left a couple with some members and I will leave an additional one. I spoke to her this morning. If we go down the list, who's most likely to be the abuser? The son. It's really upsetting if we have notions about, you know, there's no love like that between mother and son. Well, there's no abuse like that between mother and son either. If you go down the list, who's the perpetrator? Father, mother, daughter, son, stepson. Neighbours are going up on the list, maybe second after family. You can count on people you know for the best and for the worst. The nature of the intimacy in that relationship means that the well-intentioned ones will provide some of the best kind of care and run themselves off their feet providing for you, and it's most likely that abuse will occur from family members as well.

My concern is that the Substitute Decisions Act doesn't adequately provide safeguards to ensure that someone who wants to be your guardian clears even some basic checks. You can't be a block parent without running a CPIC check first, but you can be a guardian. The public guardian and trustee currently is meant to review all applications for guardianship and doesn't check to see if the person is an undischarged bankrupt, doesn't run a CPIC check to see if they've got fraud convictions. I think the stakes are higher there.

We talk about amendments related to powers of attorney on page 14. Again, I think the formalities surrounding the execution of a power of attorney are important. We heard yesterday that some people think there are privacy issues. I'd say too bad; the stakes are too high. A power of attorney is not a private contract between two parties. It's one that third parties rely on. Real estate is bought and sold; access is given to safety deposit boxes. In a sense it's like marriage; it's not in personam, it's in rem. It affects the community; you have witnesses to it. They should be people who aren't in a conflict of interest. Excluding the adult children is a good start. Yes, other people besides children can be heirs, but the fact that a safeguard is not 100% effective doesn't mean it shouldn't exist. It's better than nothing.

Page 16, amendments related to guardianship: There's a relaxing of the restriction that people who are providers cannot be guardians. Now they can be guardians of last resort if there are no relatives, and even in preference to the public guardian and trustee. I believe that if you're going to go down this road at all, you can look at a continuum of health care providers or providers. I'm not



terribly troubled by a case manager working for a non-profit agency that doesn't charge fees being someone's guardian for property. I'm very troubled by the idea of unregulated operators of a seniors' home becoming the guardians for property for residents in those homes and then writing themselves a cheque for any amount they want as they jack up the fees for the à la carte services. There are rent controls for now; there are no controls over the cost of à la carte services. That's just a formula for abuse.

Page 18. I'd like to talk about the widespread use of statutory guardianship. It's been a slippery slope. We had the Mental Incompetency Act before April 3 and that wasn't frequently resorted to. It was antiquated and cumbersome; it was court-based. If you're a psych patient, though, an inpatient or outpatient, you could be determined to be financially incapable by one physician and with the stroke of that doctor's pen you're placed under the public trustee. It was really efficient. It was also appropriate for people of fluctuating incapacity, because the same doctor could lift it a month later when you've settled down and you're financially responsible again.

On April 3, with changes to the legislation, that model, which is so streamlined, was extended to people outside of psych settings. You could be in a nursing home. But it was a cautious extension. The person had a right to refuse it. Now with these amendments, statutory guardianship, which is not court-based, which proposes a tremendous amount of authority with an assessor, can be applied to anybody in the community, and provided they don't refuse the assessment in the first place, they can have statutory guardianship imposed on them by an assessor.

I know there's some quality control in the office of assessors. They're not a self-regulating profession. We've heard stories about fees that only constitute gouging that are then passed along to the estate, which suggests some assessors are practising economic abuse on vulnerable people. Many of them are regulated health professionals or other professionals, but those standards probably don't apply when they're relating to a person as an assessor, because there are no standards for that. There are internal standards in government, but it's not a self-regulating profession. When we repose that much authority on them, we ought to look at what kinds of standards we have for the individuals we're giving that kind of authority to.

I just think it's so seductive to say, "The court-based system is so expensive and cumbersome; let's have a streamlined one that's not court-based." As I say, the precedent in the Mental Health Act was one that was easy to turn on and easy to turn off. For people of fluctuating incapacity it was a good fit.

What we've got here now is that statutory guardianship is now easy to turn on. If the patient who's been determined to be incapable, the individual, wants to turn it off, if he can find an assessor who says he's capable, that's one way to do it and that's good. Otherwise, they have one kick at the can to go to the Consent and Capacity Review Board. But after six months, to turn it off they've got to go to court, which is a really onerous obligation to put on the individual. If you can turn it on that easily, you should be able to turn it off with a board hearing right through.

I'd like to talk, on page 21, about the confidentiality of clinical records. This is an easy-to-miss, I suppose, reg-making power added to section 90 of the SDA, but it would allow virtually anyone to go through another person's medical records. I'm least concerned about (e.4)(iii) in the middle of page 22, that allows the public guardian and trustee to have access to records. They are a public, accountable organization. As civil servants, the individuals take an oath of secrecy to the crown; they're covered by the freedom of information act. They have that kind of public duty and are individuals who have their livelihood at stake if they abuse their authority.

Up at item (i) we have an assessor. As I said before, there are some standards that apply to them but they're not really statutory standards. Assessors in their day job might owe a duty of confidentiality to their patients. That doesn't mean those standards apply when they're assessing someone. The really scary one is the middle one, (ii): any person who states in writing an intention to make the guardianship application. That's that person who wasn't going for something high-stakes like being a block parent, so he didn't need a CPIC check. We're talking anybody.

Now, (e.5), what kind of comfort does that give us that there can be regulations made governing the use and disclosure? You can't put an offence section in those regulations. That "any person"—you don't have anything else to threaten them with. They're not going to lose their livelihood; they're not going to lose their professional status. They may not have any, and you can't put an offence section in there. What clout do you have to say, "Once you get that medical record, you can't give it to the local newspaper"? I'd suggest you have none. I think matters as important as this need to go in statute and not be the subject of regulation, and there needs to be restrictions.

#### 1050

Finally, I'd like to talk about the last page, repeal of the Advocacy Act. We note its passing. We note that we've heard the government say that its repeal of the act doesn't represent in any way a repudiation of the need for advocacy for people with disabilities, but rather the need to create a different vision of how that service can be delivered.

We want to offer our resources and our 12 years, almost 13, of experience to assist the government in shaping that vision in the focus groups that the Ministry of Citizenship has already commenced, for which we are grateful. I think there's already a converging vision that you certainly don't need to replicate something on the scale as ambitious as the commission, but you are probably going to need some supervisory body that can create some curriculum for advocates so we can have confidence they have some basic shared knowledge, some standards, that they agree that they will not abuse their authority, if we're going to give them some authority, to have access to people in some settings. We have to have some sort of licensing mechanism to deal with that.

I'm going to pause there and entertain questions.

**The Vice-Chair (Mr Ron Johnson):** Thank you, Mr Giuffrida. We've got about three minutes per caucus.

**Mr Marchese:** Just some quick comments and to thank Mr Giuffrida for the presentation. I found it very



reasonable and balanced, which is mainly the theme of your presentation. I like the fact that you pointed out that we shouldn't canonize nor demonize people, and again, that's part of what we need to do as society, and look at the various extremes and that all extremes seem to be a problem, and how we find the middle ground to deal with some of these problems is something that I found very useful.

I like the point you made about standards, in terms of whose standards are we living by? I think you pointed out that the standard we should be living by is what the patient would like to know. I think that's the way you phrased it. That's our concern as well, in terms of trying to understand how we can abuse power and how individuals lose their power in that process. So I just wanted to note those comments and I found your presentation very good. I hope the government members will read it carefully as well.

**Mrs Boyd:** I was interested, particularly juxtaposed to the previous presentation, in the concerns that you raise in terms of not just faradic stimulation, but the whole issue of aversive behaviour modification. Your solution, then, would be that it ought to be very strictly regulated, rather than the very permissive thing that is put in the act, which would allow any substitute decision-maker to allow aversive conditioning to occur.

You're saying what we need to be looking at is an amendment that allows it to occur under very specific circumstances that protect the client and that, I would think, prevent a widespread use of this. Aversive behaviour conditioning used to be used routinely in training schools, used to be used routinely in the various institutions for the developmentally disabled, used to be used routinely in psychiatric hospitals. Your concern is that we limit that in such a way that when the very special and specific case comes along it's possible for it to be used, but it's not possible for it to be used in an increasing manner, as we in fact see it being in some jurisdictions.

**Mr Giuffrida:** Yes, that's right. There's always the problem in an institutional setting, where the treatment interests of the individual must compete with the institutional interests; for example, to maintain order and discipline. The line gets really fuzzy about when that intervention, when that punishment is in the patient's best interests and when it's just to maintain order and discipline, which is an institutional goal. I think you do need external standards. Particularly if resources are reduced, it's going to be really seductive to keep people in line using punishment and just put a label on it, call it treatment and then say: "Well, we're trained professionals. It's beyond your purview." I don't think we can accept that.

**Mr Clement:** Thank you, gentlemen, for your presentation. I just wanted to get some elaboration on the last section, which deals with the repeal of the Advocacy Act. What I take from your presentation is that we all recognize that in our society as a whole there is a need for advocates in certain well-documented situations, and that there may be a role for some government involvement—do I take it for educational purposes—is that what you're trying to get at—to make sure there is a body of information available to those who wish to act as an advocate in

a particular situation? Is that the direction you'd like to see us go in?

**Mr Giuffrida:** The concern is not that government actually deliver any of the services, but that it makes sure an infrastructure exists that can deliver those services. I think the independence from government continues to be an important feature of any advocacy model. Appropriate stakeholder representation as far as governance—I don't know that it needs to be 100% people with disabilities, because I think family members and enlightened service providers also have important insights. The public needs to have confidence, if someone shows up at the door of an institution and says, "I am an advocate," that the person has some basic understanding of what the disability is about, how the institution functions; if they're going to exercise a right of authority to look at records and have access to the client, that they're not going to abuse it and they understand the limits of it. Even some skeletal structure to manage and administer that could ensure a high standard there and be independent from government.

**Mr Tilson:** I think we appreciate your offer to assist in any rights process and I'm sure the ministry will be considering your offer.

I would like to ask a question specifically with the previous speaker, who I doubt would appreciate your using the words "cattle prod." Her husband is a medical practitioner, I believe. She seemed to be confident with the standards that were used. She made it quite clear this is the last resort; nothing else worked.

**Mr Giuffrida:** As I say, I think the fact situation she presented was the most compelling case for allowing the use of faradic stimulation. That is not to say that each and every case in which it would be applied will be as compelling or that the parents would be as thorough and conscientious as she and her husband were. We need to fashion laws that deal with best-case scenarios such as she presented and deal with worst-case scenarios, and that's why we need standards.

**Mr Tilson:** I'm looking at the last bullet point of your comments on page 9. Do you think in her type of case you should be making her go to the Consent and Capacity Review Board? I think you mention three to six months, on that basis, in her type of case.

**Mr Giuffrida:** I don't want in any way to suggest I'm an expert in this area. What I've heard is that positive reinforcement can have permanent beneficial effects but that negative reinforcement or punishment is something that needs to be applied forever. I think, before we sentence someone to being punished routinely for the rest of his life, there ought to be some oversight of it to make sure that when that particular treatment is withdrawn, no less invasive one will maintain him at a reasonable standard.

**Mr Tilson:** I guess the concern I have is how far the state is going to get into the face of a private individual. These people are seeking good—

**The Vice-Chair:** I'm going to have to stop you there and move on to the Liberal caucus.

**Mrs Caplan:** Just to follow up and finish that point—I do have another point I want to get to—I see the issue in terms of what is appropriate accountability, because the situation you have is not where an individual is consent-

ing but where someone is consenting on his behalf. Whenever you have accountability, you have to have standards and monitoring.

I think what you want to put in place is not something that gets in the face of parents and families who desperately want appropriate treatment for their loved ones, but you want to make sure that the treatment is appropriate, that it is monitored and that standards are put in place. The concern I have is that this treatment will now be available outside of a Comsoc facility, anyplace where you may not necessarily have that kind of thing. I think that's the issue, just to frame it in a way—I'm very sympathetic to Mrs Singer and was looking for a way for her to have access other than going to the minister for an exemption. I want to be very clear on that.

The question I have for you is, were you consulted by any of the ministers but particularly the Minister of Health and the Attorney General prior to the tabling of this legislation?

**Mr Giuffrida:** No. It's unfortunate. It's the first time in perhaps 10 years that I've been involved in law reform that we didn't have an opportunity to comment on draft legislation and have feedback. Perhaps some of the more technical points that we raise here needn't have taken up this committee's time.

1100

**Mrs Caplan:** That was the reason I asked the question. The minister had told us and I'd just assumed they had, and from the presentation it became clear that there were some technical things—for example, I don't think the definition of whether it's an appeal or—that should have been dealt with before and I hope they will take your suggestion.

My concern is that this legislation has no mandate given to anyone to ensure that there is any education or training, or it's not given to the colleges and it's on the rights advice that may or may not be given. I see that as an appropriate mandate for the Psychiatric Patient Advocate Office. I know you do some of that now. Just for the information of the committee and perhaps some of the members and people watching, could you tell us a little bit about what you do, and also would you be able to undertake some kind of standard-setting for training, both for rights advisers and future advocates? Is that a reasonable expectation of you?

**Mr Grant:** Yes, we're involved in both rights advice and advocacy. The program started as an advocacy program and then in 1987 we assumed responsibility for rights advice.

To answer your question as to the ability of our program to take on some kind of a training role, to the extent that we have the resources we have, we can probably do some of that. On an ongoing basis, that's questionable but certainly initially.

For example, I know there's a possibility of our program being asked to assist the Ministry of Health. If rights advisers go into psychiatric facilities in general hospitals, for example, and rights advice is limited to that aspect under the new legislation, and then of course there's still rights advice in the psych hospitals where we are—that we've been asked to consider assuming some kind of a training role, will we be prepared to do that?

Would we be prepared to assume responsibility for running the program in those facilities? I don't know.

**Mrs Caplan:** Right now, you only have a mandate for the psych hospitals, the schedule 1s, or no schedule 1s?

**The Vice-Chair:** I'm sorry, Ms Caplan. We're out of time. Mr Grant, Mr Giuffrida, I'd like to thank you for your presentation. We have to move on.

**Mr Clement:** On a point of order, Mr Chairman: I believe the presenters did mention that they were part of the Ministry of Citizenship, Culture and Recreation focus group on advocacy, so they were consulted.

**The Vice-Chair:** That's not a point of order.

**Mr Clement:** Oh, I'm sorry, Mr Chairman.

**Mrs Caplan:** They didn't say that.

*Interjections.*

**The Vice-Chair:** Excuse me, Mr Clement, Ms Caplan.

### CHEDOKE-McMASTER HOSPITALS

**The Vice-Chair:** The next presentation is going to be by geriatric psychiatric services, Chedoke-McMaster Hospitals, Dr Adrian Grek. Good morning, doctor.

**Dr Adrian Grek:** Good morning. I'd like to confine myself to just one issue, a perhaps unanticipated complication of the existing legislation which I hope could be amended.

I submit that the present legislation hampers humane, expeditious and practical care by preventing qualified physicians from certifying certain elderly psychiatric outpatients as incompetent to manage their estate, and I suggest that the legislation be amended to restore such authority to qualified physicians.

My special interest is in the psychiatric problems of older people. My patients are all elderly. Most of them have serious mental illnesses, including dementia, depression and delusional or paranoid disorder. Often they suffer from disabling physical illnesses as well.

Many of them still live in their own homes, places which of course give meaning and security to their lives. There are several who have no families or friends to speak of for various reasons, perhaps because they've outlived them, or perhaps because their behaviour has frightened other people away, or because their illnesses interfered with the development of lasting relationships in earlier life or because they have been displaced from their origins and from their connections. Psychologically, physically and socially these are very vulnerable people in very fragile circumstances and they are at risk of neglect, self-neglect, exploitation and institutionalization.

The team of which I'm a part at Chedoke-McMaster Hospitals, a team which comprises physicians, social workers, nurses, occupational therapists and a psychologist, dedicates itself to the assessment of the circumstances and requirements of such people and to finding ways to ease their distress and to support their autonomy.

At the request of family doctors or of community agencies, we see and help to look after such patients in our clinic or in their homes and maintain close links with formal and informal caregivers.

Part of my work over the years has included the specialized assessment of the competency of sick, elderly people to manage their affairs and to make choices which



promote their best interests. My initial assumption in each case is that the person is competent and I deeply respect a patient's right to choose for him or herself. I believe, though, that it's my responsibility to try to find and demonstrate competence in situations where others may have questioned it. I do not take lightly a finding of incompetence; it can be a major blow to a person's self-esteem and independence. An assessment such as this is rarely an end in itself; it's the first step to helping a patient find the means to an autonomous but appropriately protected life.

Unfortunately, some of our patients are not competent to manage their finances because of profound impairment of judgement and insight. This impairment, sometimes permanent, sometimes temporary, arises from a loss of memory or from an inability to work through complex decisions or from the pernicious and misleading influence of delusions. It may result in an inability to pay for necessary accommodation, food or assistance with everyday activities. Without these, the chances of suffering, deterioration, even death, increase and hospitalization or institutionalization, instead of less intrusive measures, are often thought inevitable to stave them off.

The existing legislation interferes with my ability as a psychiatrist to arrange prompt protection for outpatients who desperately need it. It exposes them unnecessarily to intrusive and confusing duplication of assessments, to expense potentially beyond their control, and to cruel and dangerous delays in the provision of protection and support.

As a psychiatrist, I can no longer issue certificates of incompetence in respect of my outpatients. I retain the authority to do so in the interests of inpatients and so I presume therefore that my skill and motivation in this field are not in question, nor those of psychiatrists in general.

If I recognize such incompetence in an outpatient during the course of an often lengthy assessment, often done with quite a lot of preparation in conjunction with colleagues from other professions and agencies, often with an interpreter, often in an immobilized patient's home, I'm now effectively unable to obtain the immediate protection of the public trustee for the patient.

Rather, I have to advise the concerned family or friends—who very possibly don't exist or are out of the picture or are themselves overwhelmed or frail or have interests in conflict with those of the patient—to seek a capacity assessment, for which they will be financially liable and for which there isn't a set or a maximum charge. I understand that the cost of such a capacity assessment may be substantially more than the fee OHIP pays me and other psychiatrists for our psychiatric consultations which include, but are not limited to, an assessment of capacity.

If such family or friends are missing or are not able or willing, then I, or the hospital where I work or my colleagues, may seek an assessment of capacity by a capacity assessor. We would become liable for the cost of repeating an assessment I've already done. OHIP is going to pay me for my assessment anyway and the hospital is already paying for the time and efforts of my non-medical colleagues.

In due course, a capacity assessor may be found. Usually less experienced than my colleagues and I are, he or she may take longer than we did to perform the assessment; he or she will have to subject the patient to a repetition of intrusive and perhaps unwelcome personal questions. In my experience so far, capacity assessors have wanted to take my opinion into account in the preparation of their own reports and recommendations. I'd like to oblige, but cannot do so without proper authorization.

Added to the patient's burden then is the need to worry about a form authorizing the release of psychiatric information. If the patient's not competent to sign such a form, another layer of capacity assessment and substitute consent is added to the process.

#### 1110

If the patient is unwilling to agree to a capacity assessment, the putative family or friends may seek a judicial solution, again possibly at considerable inconvenience and expense.

If the patient is at imminent risk by reason of incompetence to manage his or her estate, then I or the putative family or friends may seek the intervention of the urgent investigations branch of the office of the public guardian and trustee, but so far, this has not been a rewarding resort. My authority to breach the patient's confidentiality in an approach to the branch is not clear in the existing legislation or regulations, and in any event, the branch has been very slow to respond to requests to intervene.

Before the introduction of the present legislation, I could issue an outpatient certificate of incompetence as soon as my assessment revealed incompetence and its attendant risks. The office of the public trustee could promptly investigate the situation and act, if necessary, to protect the patient's assets; could also act in the patient's best interests by superintending the use of those assets according to the best advice available. Now weeks or even months can pass before the patient is appropriately protected. This can be dramatically catastrophic if a predator seizes the opportunity to defraud a vulnerable patient.

It is less dramatic but no less tragic if the patient has to move into a hospital or an institution because the law intended to protect the autonomy of frail elderly citizens actually delays, beyond the point of usefulness, measures to support that autonomy at home. Once a frail elderly person is institutionalized, it's almost impossible to restore him or her to the home they've lost.

I wouldn't at all like to leave the committee with the impression that I believe in the infallibility or superiority of a psychiatric judgement of competency or incompetence in any case. The former legislation made ample and welcome provision for appeals by patients, families and advocates to a board of review. I am unable to see, however, how the rights of patients are advanced by denying them the protection and assistance that may promptly follow assessments by qualified physicians working in conjunction with resourceful, compassionate and expert multidisciplinary teams. Nor can I see how the circumstances of frequently poor and vulnerable elderly people with psychiatric illnesses are enriched by the requirement that their advocates squander money on

duplicating adequate and adequately reviewed assessments of their competency.

**Mr Tilson:** Thank you for your presentation. Many of us had presentations in our own ridings on this whole topic when these three bills were before the former government. Most medical people, in fact I don't think there was anyone, any medical health provider, who didn't come to me and say they were simply made dizzy by the proposals that were being put forward as to the very topics you're talking about. They didn't know which way to turn. They were worried about liability. They were worried about breaking the law. They didn't even understand it.

With respect to the issues you have raised, if you were included in the category designated as assessors in the legislation, under the regulations of the legislation, of Bill 19, wouldn't that solve much of what you're talking about?

**Dr Grek:** I think it would.

**Mr Tilson:** It's as simple as that, so we'd make a regulation designating different categories of who are assessors and who are not.

**Dr Grek:** Yes.

**Mr Ed Doyle (Wentworth East):** I have a very simple question for you, and that is, do you get the impression these days that you have to become a lawyer before you can become a caregiver? Are we reaching that point?

**Dr Grek:** Not really. The law is complicated, but the clinical issues are very complicated themselves and I don't think they can be separated. I think the complications to which I refer here may just have been unanticipated before the problems attested in practice.

**Mrs Caplan:** Nice to see you again, Dr Grek. My questions really relate to the issue around the need to let somebody know they've been found incapable. Under the Mental Health Act, you're required to tell someone when you have found them to be incapable; you're also required to let them know that they have a right to appeal. Do you find that difficult or onerous?

**Dr Grek:** Again, not particularly; it's not always pleasant, but I think it's my duty as a physician to let patients know what course of action I either think I should take or that I have to take in respect of them.

**Mrs Caplan:** I knew that that's what you were going to say, because under the Mental Health Act that's just been the normal course. It's not always pleasant. Do you see any reason why any patient in any setting, whether it's under the Mental Health Act inpatient or in a schedule 1 or someone who's found incapable for the purpose of any treatment—now, this is on the treatment side—shouldn't be told that they've been found incapable of making a decision about their own treatment and be told that someone else is going to make the decision and that if they object they have a right to appeal?

**Dr Grek:** I believe that it is a physician's responsibility to inform a patient of such a thing. On the other hand, and maybe this isn't the question you're asking, I also think it's a physician's duty to let a patient know of his or her right to appeal if there is one, certainly. I think it can become problematic if the physician or other health care provider becomes the instrument of arranging such an appeal, because there is a conflict of interest.

**Mrs Caplan:** I agree with that, and that's not what I'm suggesting. Would you be surprised to know that this legislation imposes no obligation outside of the Mental Health Act for anyone who evaluates or assesses someone incapable to let them know that they have found them to be incapable; there's no obligation to let them know that they have a right to appeal that finding? Would that surprise you?

**Dr Grek:** Well, I probably should have read the bill in more detail.

**Mrs Caplan:** What I'm suggesting is that the same rules that apply to providers such as yourself under the Mental Health Act and that apply to the public guardian and trustee's office just apply to anyone. Do you have any problem with that?

**Dr Grek:** No.

**Mrs Caplan:** Thank you. It just seems to make common sense. I use that term advisedly around here.

The other question that I have is on the issue of confidentiality. I agree with you about your need to be able to share with the office of the public guardian and trustee, but there is a provision that was raised by the last presenters that would permit anyone who applies in writing to make an application to be appointed a guardian—anyone—to receive all medical records, including all the sensitive mental health records. Do you have concerns about that?

**Dr Grek:** Well, I do. I haven't been able, perhaps because of my own inexperience in reading laws, but I did seek legal advice on the question as well. I've been unable to fathom just where my authority as a physician, as a psychiatrist in possession of such records, actually arises to release information in all sorts of circumstances in this connection, and it's not at all clear to me or to the lawyer who advised me.

**Mrs Caplan:** I think that puts it very well. The last question that I have relates to the previous presentation as well. At the present time, the Psychiatric Patient Advocate Office has responsibility only for provincial psychiatric hospitals. You deal with them all the time at the Hamilton site. This legislation does not expand their mandate to include any of the schedule 1s or in fact to take over any of the responsibility when the commission is phased out. I'm talking now about the PPAO. This does not give them any mandate to expand their services to fill that gap. Do you believe that they are the appropriate organization, given their experience, to provide that service in schedule 1, in general hospitals, and perhaps in community mental health programs, as well as the psych hospitals? Or do you think there should be a separate and different other agency?

**Dr Grek:** I don't really know.

1120

**Mrs Caplan:** Do you think the people, whether they are in a psych hospital or a general hospital or a community mental health program—I'm talking now Mental Health Act—should have the same rights, or do you think people in psych hospitals should have a special status?

**Dr Grek:** No. They should have the same rights.

**Mrs Boyd:** Thank you very much for the presentation. I was very interested in the viewpoint that you provide, because it is a little different. I had a couple of questions.



I'm glad that Mr Tilson asked about whether a regulation listing physicians in your situation as assessors would solve the problem, and you seemed to think it would, that that would be good.

I'm wondering, if that were there, would there also need to be a regulation that would free you to share the information with an assessor who was not you? On the third page you talk about not having the authority currently to share that information without going through the same kind of process again. Would it help, if there were to be such a regulation, for that regulation to clearly specify that it enables you to share that information with any other assessor who may have been called in?

**Dr Grek:** Yes, I think that would be helpful. If I may add, I think it would also be helpful if the regulations could clarify a physician's authority to initiate an overture, in respect of an outpatient, to the Office of the Public Guardian and Trustee, because at the moment I believe the regulations and the legislation allow us to respond to a request from that office, but it's less clear if we've in fact discovered a vulnerable person and need to notify the office as to how much information we can provide, especially to alert them with details as to the urgency of the problem.

**Mrs Boyd:** Of course, you're seeing more and more outpatients as deinstitutionalization occurs. So that's going to be a growing problem, and if you're the first-line caregiver, you're very often the one who would see some of those. You're just looking for a mechanism to alert the rest of the system, that you as part of that team would like to see something happen. I think that sounds very reasonable.

I think on the last page you're expressing real concern that the avenue for appeal by families and the patients themselves and advocates to a board of review seems to have gone by the board in this version of the legislation. Can you expand a little bit more on why it's important to have that avenue for appeal, what that does in terms of the confidence that people have in one another as acting in the best interests of the patient?

**Dr Grek:** I was commenting less on the state of appeal in the present legislation than I was on the sense of security that I believe the old legislation provided both to me and I presume to patients and their families that my decisions were not merely arbitrary or merely the last word on a matter as important as—I'm a doctor, not a judge. I do believe that the decisions I make should, as long as it doesn't hamper the provision of treatment in a timely way, be reviewed by an outside, independent authority.

**Mrs Boyd:** You'd like to see a restoration of that then?

**Dr Grek:** I actually was not aware, I have to admit, that the right of a family to appeal against a finding of financial incompetence—well, I no longer have the right to make that finding anyway, so they have nothing to appeal. For inpatients, they retain the right to appeal my finding.

**Mrs Boyd:** You made a comment about the inability, with its current budget and resources, for the guardian and trustee to undertake these urgent investigations, and

I gather that's an ongoing problem. An urgent investigation means something might happen immediately.

**Dr Grek:** Yes.

**Mrs Boyd:** You would like to see that taken note of in terms of the administration of this process, because very often, as soon as there's any whisper that there might be an open door, I guess a lot of assets disappear fairly quickly, don't they?

**Dr Grek:** Well, I think in some cases they can.

**The Chair:** Thank you, Dr Grek, for your presentation and candid answers.

**Mrs Caplan:** On a point of order, Mr Chair: I put it to Mr Clement, who I know likes to be accurate in his concerns that he places on the record. I checked with the PPAO, and in answer to my question as to were they consulted prior to the legislation by anyone, in fact they were not. The consultations that took place two weeks ago, after the legislation—and in fact it was not a consultation; they were part of a focus group. So for your information, the answer they gave was absolutely correct: They were not consulted prior to the tabling of the legislation.

**The Chair:** Thank you, Mrs Caplan. As we know, that is not a point of order but thank you for the information. Mrs Boyd.

**Mrs Boyd:** I think this is a point of information. In the presentation that we've had from the psychiatric advocates, mention was made of this list of elder abuse issues that had occurred that had been presented by one of the police officers. I wondered if we could table this for the information of all the committee, because I understand everyone did not get a copy.

**The Chair:** Is there any objection? Since not, you can table it. We'll obtain copies and deliver it to members.

#### ONTARIO ADVOCACY COALITION

**The Chair:** The Ontario Advocacy Coalition, Mr Endicott and Ms Harman. Welcome. Thank you for coming today. If you could identify yourselves for the purposes of Hansard, we'd be much obliged.

**Mr Orville Endicott:** I am Orville Endicott, the coordinator of the coalition, and I apologize for not informing the clerk of the other people who would be part of our delegation. They are Mae Harman, one of the two co-chairs of the coalition, and Patricia Bregman, from ARCH, which is a member group in the coalition. I'm going to turn things over immediately to Ms Harman.

**Ms Mae Harman:** Thank you. I'm sorry that our other co-chair, Ralph Evans, cannot be with us today. He represents the Association of the Physically Handicapped (Windsor and Essex County), and neither his organization nor ours could afford the train fare to bring him here today. It's always a problem for Ralph to get here anyway because he has a large wheelchair and only some trains carry wheelchairs and a couple of times he has missed his train because the taxi that accommodates wheelchairs has not got there in time. I'm sure Ralph is with us in spirit today, anyway.

The Ontario Advocacy Coalition is made up of 47 member organizations representing seniors and people with disabilities. The prime purpose of the coalition has

been to obtain effective advocacy legislation, to monitor its progress, to criticize when we felt it was off track, to make positive recommendations for change and improvements in the service, to help educate the public about advocacy and to support the work of the body legislated to conduct the program in so far as it met with the principles which we feel are fundamental to advocacy.

1130

The announcement that the Advocacy Act is to be revoked has been met with dismay, consternation and anger by those of us who over the last 15 years have studied, discussed, written, presented, argued, demonstrated and compromised in the interests of obtaining legislation to protect vulnerable people. Now, after all the time and energy we have invested, we must begin again from scratch the fight for a legislated framework for advocacy, and this in a climate which judges the vulnerable as losers who must be punished by further loss of rights, dignity and independence.

As a senior and a volunteer, I am very angry about both the loss of this legislation, which, while not perfect, we felt could provide effective service, and the waste of my personal involvement along with that of my colleagues, some of whom have been involved much longer than I. At the same time, I cherish my relationships with the members of the disabled community, who have by their efforts, commitment, sacrifice and good humour inspired and challenged me to stay involved and continue to actively advocate.

The underlying theme and purpose of the Advocacy Act was to empower vulnerable people by helping them to understand their rights and the choices available, assisting them in carrying out their wishes and providing mechanisms whereby they could participate in the process of developing advocacy services.

That many of our most vulnerable adults suffer from maltreatment at the hands of their caregivers, either family or institution, is no secret, as witness the number of court cases and coroners' inquests which have come to the attention of the public through the press.

Early in my membership in the Ontario Advocacy Coalition, as a representative of Canadian Pensioners Concerned, I went in 1990 to Orillia to participate in a demonstration outside the building where a coroner's jury was investigating the death of Joseph Kendall, beaten to death by a fellow resident in an unlicensed boarding home.

Like child abuse 50 years ago, what we know about abuse of older people and the disabled is but the tip of the iceberg, but it is through those cases which come to the attention of the press that the general public is becoming aware that the old and the disabled are often very vulnerable.

Dependency on others for care and treatment tends to deprive people of the right or the possibility of speaking out on their own needs and wishes. As with children, old people are often fearful that worse punishment will befall them if they complain, and who wants to admit to being abused by their own children? Being dependent on others may have robbed them of any sense of having rights. So they keep quiet and endure. Society's worship of the

young and beautiful robs the old and the handicapped of their sense of worth and dignity.

According to Professor Dick Sobsey of the University of Alberta, disabled people are two to 10 times more likely than others to become victims of repeated physical and sexual assault. A phone service from my local police station repeatedly warns me of current scams to persuade seniors to make unnecessary repairs to their homes or withdraw sums of money from their banks. Caregivers, family and otherwise, sometimes misuse the funds of those in their care. Ironically, the Provincial Auditor disclosed the misappropriation of residents' funds by staff in provincial institutions on the very day Bill 19 was introduced in the Legislature.

Psychological abuse is another kind of suffering inflicted upon many vulnerable people. Failure to provide adequate care, empathy and compassion is abuse also. Sometimes a caregiver is herself too stressed to give care and may lash out at the person she is caring for. Overworked and underpaid staff find it difficult to deliver tender loving care. Even before the recent rounds of cuts in spending on health care, one chronic care hospital in Toronto was trying to make ends meet by requiring ambulatory patients to stay in bed all day in order to reduce staff time.

The history of the Advocacy Act goes back to the early 1980s when a member of organizations, and especially ARCH, now titled A Legal Resource Centre for Persons with Disabilities, and Concerned Friends of Ontario Citizens in Care Facilities, began to lobby the provincial government for legislation that could make advocates available to handicapped persons and seniors who were unable to speak for themselves in regard to the inadequacies of the treatment they were receiving or the abuse they were experiencing. Concerned Friends developed a model bill during this period. In 1986 the Ontario Advocacy Coalition was formed by organizations of persons with handicaps and seniors to jointly pursue legislation.

The Liberal government of Premier David Peterson recognized the need and called for a review of advocacy for vulnerable adults, which resulted in the late Father Sean O'Sullivan's report in 1987 entitled *You've Got a Friend*. O'Sullivan, as we know you realize, had been a rather celebrated Progressive Conservative member of Parliament. We had reason to expect in the late 1980s that advocacy for vulnerable persons would not become the political football which it has sadly turned out to be.

O'Sullivan wrote in his report, "The lack of coordinated advocacy services accessible to all vulnerable adults requiring assistance is a profound injustice." In the executive summary, he stated: "Ontario needs advocacy. More particularly, we as Ontarians need to be advocates. Most of us already are. We can do more. If we are to improve our society, we must. Primary responsibility for advocacy education and the development and support of advocacy services is the proper role of government."

Writing back in 1987, Father O'Sullivan deplored the fact that the system lacked a clear mandate to provide advocacy services as there were no uniform standards of service or training programs for advocates, and those who



did advocate were hampered by the lack of a clear right of access to care facilities, clients and clients' records.

The then Attorney General, Ian Scott, himself now handicapped following a stroke, was preparing to bring forward legislation following the 1990 provincial election, but the government changed. The NDP did bring forward a bill, which was proclaimed in 1995 but, alas, is to be trashed by the passage of Bill 19 before the commission had time to organize and demonstrate what it could do. Removal of the bill undermines the rights and safety of all vulnerable people. The principles which the Ontario Advocacy Coalition consider fundamental to advocacy are attached to this report.

I'm going to ask Orville Endicott to continue the presentation.

**Mr Endicott:** I wish we had time to go through those 15 fundamental principles that the coalition has identified. I suppose I hope equally fervently that the minister at some point in time will be prepared to sit down with us so that we can talk to her and to her staff about them. We don't have time to do that this morning.

I thought I would simply consider with you for a minute some of the most fundamental issues that you are going to be considering, not only with respect to advocacy, but with respect to the entire content of Bill 19.

It is a delicate attempt, this kind of legislation, both what we have in effect now in the province and in Bill 19, to balance some very basic concerns about the lives of people who are vulnerable because of disability and age. On the one hand we have the concern that these people are kept from harm, that services that can be of assistance to them are available to them and that their physical needs are met. On the other hand, we have concerns for their autonomy, for their dignity, for their right to participate in decisions that are made that affect their lives. So basically what you are balancing here is protection versus empowerment. When I use the word "versus," perhaps that's ill-advised, because I don't think we have to make a choice between one or the other. I think protection of people's rights is a fundamental part of the general protection of their status, of their health, of their wellbeing in our society.

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The reason our coalition is so concerned about the future of advocacy and about what is obviously going to be a delay in reaching that future is that advocacy is about empowerment. We take serious issue with those who have said that advocates exercise power over vulnerable persons. That is not advocacy. That would be a clear violation of any ethical standard for an advocate. It works the other way around: Advocates take instructions from vulnerable people, and that is one form of empowerment.

Another form of empowerment of course was in the whole process by which we got advocacy legislation. It didn't come from government—I've had to say this in a lot of forums over the past few years—it came from the community of vulnerable people. When you are taking the action that this legislation is in section 1 of Bill 19, don't think that you are undoing something done by the previous government; you are undoing something done by ordinary people all across Ontario in the creation of the

Advocacy Act. As Mae said, it wasn't perfect. Whatever succeeds it will probably not be perfect either, but the imperfection can be measured best by the degree to which it might have failed, or what succeeds it will fail, to empower vulnerable people.

Now I'm going to ask Patty Bregman to use whatever few minutes we've left for her.

**Ms Patricia Bregman:** I will take just a few minutes. I guess I'm here to bring you back down to the practical, because I want to help you understand in a sense why you're going to be hearing some very emotional submissions from vulnerable people.

We're pleased that the government is giving an opportunity for people across the province to present. We do think it is unfortunate—and I will anticipate Ms Caplan's question—that not only were we not consulted prior to the introduction, but we have been writing to the Premier and to the Minister of Citizenship from the day of the election. We knew what they had said, both in the Common Sense Revolution and in their response to ARCH, and we made an offer, and a very good-faith offer, to work with the government to see if we could develop another system that met the goals the government had, that met fiscal objectives but that still maintained the absolute, fundamental principles which nobody has wavered from from the beginning, which are those that Sean O'Sullivan enunciated of independence, lack of conflict of interest, incorporating volunteers and incorporating families. We have yet to get a response to that letter. We have had one consultation session in a limited focus group.

I sit on the implementation advisory committee that is intended to advise the public guardian and trustee on implementation. The first meeting of that committee called since the election was two weeks ago. We were instructed to come to that meeting—and I unfortunately couldn't go—not to discuss any concerns we had with the legislation, but only how it would be implemented. This is unfortunate. In the end, as you hear submissions which raise very legitimate concerns not only about the lack of advocacy but about the loss of rights and the lack of balance in the remaining legislation, you're going to have to take some time now to reconsider.

We are still willing to talk to you. I want to make it clear we are trying to do everything we can to assist you. I'm going to give you just one example—you'll hear many—of the kinds of concerns that we see. You're probably not as familiar with the concerns. Vulnerable people can't go to town hall meetings. Often, if they are abused, their families won't let them out of the house. They don't have the same ability to talk to people.

When you think about the promise of the professions to protect these vulnerable people, which I know is one of the proposals, I want you to keep in mind what led up to Bill 100. I've been very involved with the regulation of health professions for a number of years. I just want to remind you how many years it took the professions to acknowledge that there was abuse. Remember that the vulnerable people we are talking about cannot speak, often, cannot be heard.

We've just handled a case where a physician in a group home was found guilty of sexually abusing a



number of young men with disabilities. There have been reports of abuse over the years. The only reason our client was willing to continue was that he had an independent advocate based in his home town. It took him months before he was willing to talk to us, let alone lawyers at a college somewhere far away. You need to just remember the vulnerability.

The one story that always strikes me in terms of where the balance is—and we'll say as a proviso that we are not suggesting that families are all abusive, that families don't have best interests—we are doing this and talking about the downside only because we keep hearing that everything has to be streamlined to protect families. We want to remind you of the other side.

We had a call from a woman who was admitted to the hospital for serious surgery. She had multiple disabilities and kidney failure. She had previously arrested in the hospital and knew that she could be resuscitated and wanted to be resuscitated. She had no contact with her family for a number of years. They'd institutionalized her and thought that her lifespan was long enough. She was articulate and capable.

She went to the hospital with her landlord, who is a friend, and said to the doctors and the nurses, "I want to be resuscitated." Around midnight, just as she's getting to sleep and dozey from the medication, she hears a discussion among the nurses that the doctor had thought she was too confused to be able to make that decision, called her parents, who lived out of town, and put a DNR order on her chart. This woman went through the night and that surgery absolutely terrified as to what would happen.

Here we have somebody who clearly would have been capable, clearly had given instructions and yet was powerless to do anything about it. She had a communications disability on top of everything else and couldn't even pick up the phone without the assistance of those same nurses and doctors that had gone behind her back to her parents.

This is not, unfortunately, unusual. You'll hear more stories like that. We will be submitting a more comprehensive written brief in order to respond to some of the things we heard from the minister yesterday and to accept his invitation to try to come up with some concrete proposals.

Think about this: We've circulated two documents dealing with abuse; one is a bibliography. I distribute it because in every meeting I've been at with ministry staff they've always said, "Is there any substantiating documentation that people are being abused?" The bibliography comes out of an excellent book by Dick Sobsey, which was just published, and will give you a number of references. The article comes from the Roeher Institute, which was also just published, excellent book.

It may help you understand and put yourselves in the place of the vulnerable people and maybe encourage you to work with us to see if we can find a different way, if you're not willing to go along with the Advocacy Commission, to at least find some mechanism to ensure that people are empowered. In the long run, it will save you money.

**Mrs Caplan:** You anticipated my question, and I am disappointed to hear you were not consulted. I know I

met with you as well and it was our party's intention to dismantle the Advocacy Commission as it exists. We made the offer to work with you to find other alternatives, and I suggested there are other mechanisms that could be very cost-effective and that would work.

I'm sorry they haven't given you the opportunity to work with them to put those forward, because the point that you make is an important one, and that is the issues that were raised by O'Sullivan and the issues that were raised in the Manson report. The work that was done by Fram and his committee is just as valid today. We know there were problems with the way the Advocacy Commission was set up and that it was unaffordable. But that doesn't mean that you throw out, using the old cliché, the baby with the bathwater and that there isn't something that can be put in place.

You've made an excellent presentation, and I hope the presentations that this committee will hear will influence the government at least to open up a dialogue with you to put some of those alternatives in place. I believe that this legislation could be amended to do some of those things, that you don't need separate advocacy legislation. Would you agree with that?

**Ms Bregman:** I think that's entirely possible. We'd have to look at it, but certainly we're quite prepared to look at amendments that would reshift the balance and make sure it really does what it was intended to do, which is to enable vulnerable people to make decisions, with assistance, with support, without having to have the most intrusive act a person can do, which is take over your life.

1150

**Mrs Caplan:** I also think it's important to recognize that there are three distinct interests, not vested interests but certainly legitimate interests. Those are the interests of the patient or client or vulnerable person. That's one category. Another is the interests of the families, most of whom love them and want to take care of them. Sometimes they don't want them to be able to risk in any way and, as you've said, the balance in making choices that might involve some risk is a conflict with even well-meaning families. The third is the interests of the providers who want to offer care and have obligations to make sure that they get informed consent, although there are questions now about whether they should be obliged to let someone know that they've been deemed incapable.

I know what your answer is going to be but, on the record, do you feel that an assessor or an evaluator under this act should be required to let the individual know that they have been deemed incapable and it has been decided that they are incapable, under the law, to make decisions for themselves, and to let them know of their right to appeal at least that information?

**Ms Bregman:** I go one step further. I think at a minimum, they have to, first, tell them what their rights are and, if requested, assist them in exercising those rights, and there has to be an assurance that there will be no reprisals from a request for that assistance. That's something that exists under the Human Rights Code.

Second, to protect the care providers, you need to build in some protection for them against reprisals, because we've had a lot of calls from service providers who say:



"My boss won't let me do this because the person we're advocating against happens to be on the board. I'm afraid to do it, and we don't know what to do."

I think you need to offer protection to the person making the request, but also I think there are some excellent caregivers out there who would like to be doing more, but in this time of layoffs and fear for job protection are feeling quite vulnerable themselves. It's certainly what we're hearing. I suspect you may hear that from some of them.

**Mr Marchese:** Thank you for the submission. I'm one of those who believe that the repeal of the Advocacy Act isn't a responsible act. I've been through the Employment Equity Commission hearings. They repealed the act and said that they would have an equal opportunity plan in place, of course. We never knew what that plan was and still don't know, and we're likely never to know what that plan is. The repealing of an act in itself with the sense of somehow we're going to get something is, to me, irresponsible. So I'm very concerned and worried about what they're likely to bring in its stead.

In response to Mr Tilson's question, this is what the Minister Mushinski said about the commission, how much they had been spending and what they've been doing. She says the following, which worries me because it's indicative of her feelings around the whole area of advocacy and rights advisers, I suspect.

"I can tell you that they haven't been advocating advocacy. The only thing they've been doing is providing rights advice, to the tune of \$18 million. They're spending on rights advice approximately \$500,000 a month. The Advocacy Commission itself has not done anything other than rights advice for the last 12 months. They've not done anything about advocacy and the rights of vulnerable people at all, other than providing rights advice and, as you suggested, going into people's homes. So it's a professional bureaucracy, and it was the whole intrusive nature of that bureaucracy that a lot of the advocates themselves"—we don't know who they are—"have been so outspoken about. That's the key reason we've repealed it."

I just wanted a reaction from any one of you with respect to that.

**Mr Endicott:** I think we would be remiss if we didn't commend the Advocacy Commission for all the good work they have done. Particularly they endeavoured to get to the community level and not to establish themselves as an advocacy monopoly. That of course takes time and, under the best of circumstances, there would have been a good year to develop the capability to provide advocacy in the community. A commission, presumably, could do it in a week, be geared up to meet those needs, but that was not the direction that they chose, and we commend them for going to the community level.

**Mr Clement:** Thank you, Orville, Mae and Patricia, for taking the time to be with us this morning. I just want to say at the outset that I'm sorry our efforts to get this dialogue going haven't met your expectations. You know, Orville, I spent half a day getting heck from you guys and persons at your great debate, and I learned a lot from that process.

Of course we included you, as the Ministry of Citizenship, Culture and Recreation, in terms of our future directions for advocacy. I just want to state for the record that those efforts are in good faith. Obviously, we're not meeting your expectations and we've got to try harder to do so, but I want to put on the record that from our perspective it is in good faith.

I want to go back to Father O'Sullivan, who was a man I knew and was a man of great moral character and great moral influence in Ontario, and to the words he said, because I don't disagree with anything that you have cited him for: "We as Ontarians need to be advocates." Not a commission with a bunch of paid advocates, but "we." It's our moral duty as citizens to be advocates. Most of us already are or should be. Primary responsibility for advocacy education should rest with the government. I don't disagree with that. Maybe there are some standards we have to set and some information we have to get out.

Am I barking up the wrong tree here or is there, in his words, some lesser role than what the previous government had suggested, interpreting what you had demanded? Is there something we can do to get to the root of what Father O'Sullivan was saying?

**Mr Endicott:** One of the things I wanted to take up with you is I think you've presented us with another either/or that is unnecessary. Obviously, it is good for as many people as possible to be advocates, but in the real world there has to be organization, there has to be structure, there has to be coordination, or else people are going to fall through the cracks as they have been doing in a world where there are more people with good intentions than otherwise.

**Mr Clement:** I want to follow up on that because I think that's an important concept to get on the record here. There is, I think, a governmental role to be played, but I don't want to minimize the individual responsibility. What tends to happen in life, as you put it, is that whenever government says, "This is something we want to legislate," people as human beings naturally say: "The government is looking after it. I don't have to look after it." We have to get back to the moral justification that Father O'Sullivan had said, which is it's our individual duty, responsibility. This is part of our humanity, to concern ourselves with this. Is there something wrong in the way I've characterized it?

**Ms Bregman:** Just let me say two things. One is, you may not be aware, but when the Advocacy Commission was formed, there was enormous pressure from the community to say to that commission—and David Reville can tell you about the letters we wrote and the meetings—to insist that, number one, the advocacy not be centralized, that it not be a commission, that it be the responsibility of the communities, that all the commission did would be to facilitate and strengthen volunteer advocacy, a high priority among a number of our groups.

But what the commission was able to do was have some resources. It doesn't need to be \$18 million, but there had to be some focal point of resource and some strategic planning, because what you really want is not only individual advocates, you need systemic advocacy. If your goal is to avoid spending a lot of money on every single person experiencing the same problem, you need



to have a way to coordinate the information, the same way that ARCH preserves resources by really focusing on the priorities our community sets for us, and you'll hear a little bit about that tomorrow.

An Advocacy Commission is a way in which the broader community, including the families, can work together, outside government but with some support, to set those priorities that they think are most important for advocacy, so that we see advocacy going where it's really needed, to those people who don't have family and support.

Without some form of coordinating mechanism that can take the data that come in, that can look for the patterns—you will find in the United States, for example, legislation requires every state to have a protection and advocacy office. Australia has just set one up. Alberta is looking at it, BC is looking, Nova Scotia is.

It's because they recognize that without some focal point that can take direction from the community and not from the government and that can listen and support volunteers—volunteers are not free resources. I was at a consultation at a volunteer centre. It doesn't have to take a lot of money, it doesn't have to take a lot of bureaucracy, but it does have to take some commitment from the government and some resources. We think they are the best way for the government in the long run to save money and support families.

**The Chair:** Your time has elapsed. You certainly are an eloquent spokesman for this cause and I thank you for attending. We are recessing to 1:30.

**Mrs Caplan:** Before we recess, Mr Chairman, yesterday the Attorney General, in his opening statement, made reference to consultation, the fact that he was unaware of any time in the past when there had been statements on the record about consultation for the committee, and I have to reform part of the record. I would like to table Hansard from Wednesday, May 6, 1990, when in fact I made a long statement, but I will just very briefly give you one sentence:

"I've met with every major professional group directly affected by the recommendations and with many groups which, while not directly affected, have a stake in how the professions' legislation is framed. To date, there have been more than 350 meetings between ministry officials, individuals and groups since January 1989."

I put that on the record so that the Attorney General and the Minister of Health might know that consultation in fact is put on the record, and that my request for what they have done in the area of consultation is not an unreasonable request.

**Mr Clement:** You get a gold star.

**Mrs Caplan:** So I hope they'll reconsider and table with this committee what their consultation was before this legislation was tabled.

*The committee recessed from 1202 to 1331.*

#### ONTARIO ADVOCACY COMMISSION

**The Chair:** Our first presenter is Mr David Reville, chair of the Ontario Advocacy Commission.

**Mr David Reville:** Good afternoon. I am David Reville. I am chair of the Ontario Advocacy Commission. I am a psychiatric survivor.

Let me introduce some other commissioners: Pat Capponi, and Pat is a psychiatric survivor; Tony di Pede, and Tony is a person living with AIDS; Dr Bill Forbes, and Bill is a senior; Ms Joy Isaacs, and Joy has diabetes; Joanne Nother, and Joanne has MS; Mr Krishan Uppal, and Krishan is a senior; Kerry Wadman, and Kerry is deaf-blind.

A written brief has been submitted. It's called Advocacy: Now More Than Ever and I hope you've had a chance to take a look at that. We submitted that along with the companion document called Provincial Snapshot, which is a survey of issues and gaps in service that were brought to our attention by community groups across the province earlier in the commission's tenure.

I'll be speaking primarily to section 1. Section 1 repeals the Advocacy Act. But first I want to register the commission's opposition to other provisions of the bill.

We believe that the right to make one's own decisions is an essential right. That's why we strongly disagree with the government's decision to remove the option of a rights advice visit under the Health Care Consent Act.

We believe that rights advice must always be given by an independent rights adviser. That's why we strongly disagree with the government's decision to leave rights advice under the Substitute Decisions Act to the discretion of the public guardian and trustee. It's a conflict of interest.

I want to note tangentially that I received today a letter from the Attorney General that said no final decisions have been made to date on how this rights information is to be delivered. It strikes me as incredible that this decision has not yet been made when we're looking at the repeal of this legislation by the end of next month.

Commission rights advisers have been giving rights advice under the Mental Health Act to more than 600 people each month. How will these people get their rights advice once the commission is dismantled? If, as is rumoured, the Ministry of Health, through the minister, designates hospital employees as rights advisers, we see that as a conflict of interest. We are urging the government to amend its legislation to reinstate rights advice in the Health Care Consent Act and to ensure that rights advice is given by independent rights advisers under all legislation that requires it.

The commission has provided government with a proposal whereby independent rights advice can be delivered cost-effectively, and that proposal will be before your committee separately.

Let me return to section 1. It doesn't take long to say the words, "The Advocacy Act, 1992, is repealed." By rights it should take longer. It should take more than six words to dash hopes and shatter dreams. Decades of hopes and dreams preceded the passing of the Advocacy Act in 1992. That there was an Advocacy Act at all was a minor miracle, and that the Advocacy Act took the shape it did, well, now, that was a major miracle. The good guys had finally won.

I've been involved in the debate about what to do about vulnerable people for over 30 years and the debate never seems to change. There are three positions in the debate: Don't get involved, it's a private matter; that's position 1. If everybody is nice to everybody else,



everything will be all right; that's the middle position. You've got to say whose side you're on and you should come in on the side of the vulnerable person; that's the third position and that's the position that won the day in December 1992.

Imagine, the Advocacy Act set up a commission whose job was to promote respect and autonomy. Imagine, the act required that the disability community choose nine of 13 commissioners. Imagine, the act required that the majority of the commissioners be people with disabilities and/or seniors. Imagine, the act said that community development strategies should be used. Imagine, the act recognized that systemic change was needed; what's more, it listed where systemic change was needed at governmental, legal, social, economic and institutional levels.

Imagine, the act got the language right; it got its power relations right; the verbs, the nouns, the concepts, the plain language are unique in legislation. Words like "contribute," "empowerment," "help," "promote," "respect," "dignity," "systemic" speak on their own behalf; "mutual aid," "community development" provide their own advocacy services.

The commission met for the first time in October 1994. We set out to put in place our response to abuse and marginalization. The commission's arrival on the scene, of course, didn't end the debate. In fact, in some ways, the mere fact of the commission intensified the debate and we heard the College of Physicians and Surgeons warning darkly of possible fatal delays in necessary treatment because of the requirement to tell patients what their rights were. Not one such delay has ever occurred. One politician bemoaned the fact that advocates were "literally interfering in the private lives of individuals." That was a strange allegation, given the fact that the commission's activities were frozen before it had hired a single advocate.

It was the rhythm of big-P politics that really swung the balance, however. A few short weeks after the act was proclaimed and the commission began delivering its first services, all the available forums were occupied by the elite debaters and the debate about disability was the same as always, position 1, position 2 and position 3. The winner of that debate was duly declared and that's why today we have a different list of words, thoughtfully provided by the government. We get to see these words peppering government news releases and salting the speeches of government members.

Here are the words the government wants us to use now: "intrusive," "adversarial," "bureaucratic," "expansive," "unnecessary," "biased" and "interfering." It's a shorter list. The government is doing more with less.

**1340**

In the debate about what society should be doing about vulnerable people, the government takes position 1: the don't get involved, it's a private matter position. The government wants us to rely on the kindness of strangers. The government wants us to trust our institutions to behave properly. The government wants us to trust it too. And we do not.

We continue to believe that there is a very particular role for government in ensuring that vulnerable people

have advocates. Nine years ago, Father O'Sullivan described the advocacy environment in Ontario: Advocacy services were fragmented and inadequate. Much of the advocacy that was available was limited by conflicts of interest. Many people living in institutions had no advocacy at all. Training and standards weren't uniform. There was no coordination. Advocacy was underfunded.

Nine years later, all the problems that Father O'Sullivan identified are still there. What's changed is that the number of vulnerable people has increased. That's why we think government needs to stay in. That's why we do not agree that the government should get out.

We do not agree because we don't believe that abuse of people with disabilities is a private matter. We don't agree because we think that when somebody is beating up on your grandmother you should interfere. We don't agree because we think that you need somebody on your side when you're up against a big, impersonal institution, including a big, impersonal government. We do not agree because we don't think it's an accident that people with disabilities live in poverty, and we think that it's in nobody's interest to have people living in poverty and dependency. We don't agree that the government should be getting out of the advocacy business at a time when things have gotten worse and that many of the things that have gotten worse have gotten worse by the government's own hand.

We're not content to oppose; we want to propose as well. We have submitted *Advocacy: Now More Than Ever*. It's a brief that talks about vulnerability. It talks about what advocacy does and how it works, who advocates are. It tells the story of the commission. It explodes the mythology that's grown up around advocacy. It describes the environment in which people with disabilities find themselves. It says where the government fits in. It makes a proposal to support the interests of vulnerable people.

It's a simple proposal: The government should be funding a non-profit charitable corporation. That corporation should have three objects: community development, education and training, and systemic advocacy. The corporation should take a cross-disability approach to its work. The corporation should be governed by a board whose members are people with disabilities.

That's our proposal. It's informed by our experience and by our values. We think it's credible. The amount of money involved is \$3 million. In fiscal terms that's a saving of \$15 million. In human terms it's the least government should do.

We believe profoundly in advocacy because it's the way people take back control over their lives, because it's the way broken people repair themselves, because it's the way people can keep from getting broken in the first place, because it's the way communities care for each other.

We don't see ourselves as a special-interest group. Rather, we see ourselves as your brothers, your mothers and your friends. Anyone can become vulnerable. If we're lucky, becoming vulnerable involves nothing more complicated than waiting. We grow old. Our capabilities decline. Do we want to get pushed around when we're old? In that way we're all the same, vulnerable or waiting



to become vulnerable. We're the same too in wanting as much control of our lives as possible, in wanting as much life as possible.

I have an opportunity actually to say thank you to the commissioners and the staff for your dedication and your friendship. I want to say thank you to thousands of people in the disability community. You were generous with your knowledge. You were inspiring in your courage. Thank you.

**Mr Marchese:** Mr Reville, perhaps you can just briefly tell us why the Advocacy Commission came to be, because I'm not sure that people have a good sense of what we have in the field already. Some people probably think we have a lot of advocates out there and that they're doing the job, and if we have that, why duplicate it with this commission, of course, that is bureaucratic, intrusive, as they say, and so on. Mr Bennett also argues that perhaps we should all become advocates, and that would be the solution. Could you respond to what there is there that is inadequate in terms of dealing with what you've been trying to do?

**Mr Reville:** The approach to advocacy on a systematic basis has been piecemeal. In the 1970s, a program called the adult protective service worker was established to deal with people being deinstitutionalized from homes for the developmentally challenged. That was one program established by a Conservative government. In the 1980s, advocacy appeared in psychiatric hospitals, those operated by the government, and that was advocacy for people with psychiatric disability in psychiatric hospitals.

There are programs like ARCH and ACE, which are specialty legal clinics which provide legal advocacy and non-legal advocacy to seniors or people with disabilities. I think people began to realize that advocacy is a solution to abuse and marginalization and isolation and neglect, and that what you had to do was take a systematic approach so that people could receive advocacy no matter what their disability was and no matter where they were located. So, for instance, a homeless person who has a disability—and many indeed do—could receive advocacy services on the street; they didn't have to be in an institution or in a community program. The point was that if you have a disability, if you have a chronic illness or you're elderly and frail, you're going to need some advocacy, and it should be available wherever you are and whatever your circumstances may be.

I think we should never overlook the fact that family and friends have always been advocates, from the beginning of time, but family and friends sometimes have limitations on what they know and what they can get access to. So if your mother is in a nursing home, maybe you just don't get access to that nursing home when you need it or maybe you don't get the answers you need. In that case, an advocate is going to work with you on behalf of you and your mother. That's what sometimes gets missed out in the discussion of advocacy.

**Mrs Boyd:** Can you talk a little bit about what you mean by the building of a cross-disability network and community development?

**Mr Reville:** I think it's really important—and here again, the way we have structured services is part of the problem and government is part of the problem, and all

those of us who have tried to be in government or want to be in government know that services are delivered in these kind of silos, and if you have MS there's a whole collection of service providers; if you have a psychiatric disability, you have another whole collection of service providers, and the disability community has organized itself that way as well. So you have not only service delivery associations like the CMHA, but you'll have a breakaway association of peer support like the consumer survivor groups that have been developing over the years.

What we have discovered very powerfully is that the issues are very similar no matter whether you have psychiatric disability, as I do, or whether you're deaf and blind, as Kerry is: that you struggle with poverty, you struggle with isolation, it's hard to get a job, sometimes you feel discrimination. These issues are similar no matter what your disability is. Or if in fact you have simply become elderly and frail, you have the same kinds of problems. I think the services should be delivered in a more cross-disability way, and I think the advocacy needs to happen that way too. That's what the commissioners came to feel extremely strongly as we learned from each other and from the communities with whom we spoke.

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**Mr Clement:** I'll try to keep as brief as I can for my colleagues to have a say as well. Thank you very much, Mr Reville, for your presentation. You're always very thoughtful and you've given us a lot to think about, and I thank you for that.

I did want to come back to what Mr Marchese alluded to, because I'm trying to get at the foundation of this debate that has occurred, and Father O'Sullivan's report really is a touchstone of that. I mentioned earlier this morning about how he identified the need for all Ontarians to have that moral responsibility, and it is a moral responsibility, to be advocates. I expressed my concern that the tendency is that when government gets involved in these things, people feel it's all right to abdicate their responsibility because government's looking after it. I don't want us to get into that trap again as a society. I think we should be partaking of our moral responsibilities to vulnerable people.

**Mr Reville:** I agree with that.

**Mr Clement:** I guess my worry is, and I want your response to this, that by creating this hierarchy of rights advocates that can be separate and apart from friends and family, we are extracting empowerment away from the community and on to this artificial level. Am I barking up the wrong tree on this?

**Mr Reville:** I think you are barking up the wrong tree. We should send you our paper on volunteer advocacy, because the commission felt very strongly that it would never, ever have enough resources to provide all the advocacy that is needed, and that in fact the best advocate you ever get is somebody who loves you. We believe that anybody can be an advocate, and we don't want to discourage that.

I should point out that before Father O'Sullivan wrote his report, families and friends were doing advocacy, and they still are, and I don't think the commission supplanted one family or friend advocate, nor should it ever.



**Mr Clement:** Let me turn to one mundane question from the moral question. The commission of which you are the chair has spent \$5.1 million providing rights advice over the last little while. You're suggesting that the replacement commission would spend \$3 million doing rights advice, systemic—

**Mr Reville:** No, I didn't say that exactly.

**Mr Clement:** Well, I'm trying to figure out how we can get from \$5 million to \$3 million when you're expanding the role of the commission.

**Mr Reville:** First of all, the proposal I have made to you today does not include a rights advice proposal. I indicated that was a separate proposal. That's costed at about \$1.7 million, and you'll be receiving that shortly.

The mandate of a non-profit charitable corporation such as I have described is much narrower than the mandate of the commission. The commission had a very broad mandate which involved individual advocacy across the province, which is where the big money is. Our strategy in that respect, although we didn't get to implement it, was to deliver individual advocacy in two ways. The way that we thought was the most effective would be to have community groups deliver advocacy locally, and to enable that to occur, we were going to provide both financial and other resources to community groups so they could employ their own advocates.

We were also aware that in some communities the development had not proceeded to a stage where hiring advocates was going to be possible, so in that respect we were going to hire some advocates directly. In fact, we had a plan to hire 50 advocates, which of course would turn out to be about seven per region. If you'll be off to Thunder Bay, that part of Ontario is bigger than most countries. Seven advocates doesn't go very far in territory like that, as we discovered as we travelled the north. So that was our strategy and that's where the big money is.

The corporation that I have described would be cost-effective because what it would be providing to those community groups would be resources in terms of education and training, and then it would be hoped that some members of those community groups would want to be volunteer advocates, utilizing the training that the corporation would then provide, and other kinds of organizational support. "Community development" is the way we generally describe that approach.

**Mr Bernard Grandmaître (Ottawa East):** Mr Reville, in your opening remarks you said that you come here to not only oppose but to propose a new corporation. The intention of creating a new corporation, as far as I'm concerned, is very valid. I was talking to a member of the government at noon, in fact, and he told me that your new proposal, your new proposed corporation, would save close to \$15 million a year.

You know what the government is trying to do is to cut back and save dollars, more and more dollars, from you and just about every other service provider in the province of Ontario, to do whatever they please with those dollars, those savings.

This new corporation of yours, will it be able to provide better services or as many services as the present commission?

**Mr Reville:** No. It clearly would be \$15 million light in the amount of service that it could provide. As we were trying to figure out how to make a proposal that might appeal to the government, which has a fiscal plan, we were trying to think of how much money it would take to enhance the work of the volunteers that Mr Clement is describing and still have an adequate amount of money to do that job. That was the sum we came up with. Mr Grandmaître, I hate to tell you that what I believe is going to happen is that the advocacy effort funded by this government is going to be far smaller than before the Advocacy Commission was dreamed of. In fact, what I think is going to happen is you're going to see a collapsing and a shrinking of the activities that the Ministry of Citizenship used to undertake.

**Mr Grandmaître:** And it won't be as effective.

**Mr Reville:** Well, it will be hardly there at all. In fact, the government has always had several activity centres around advocacy. I think you're going to see those collapsed and diminished, the \$18 million the commission would have had as its budget will disappear, and that the existing effort of the government will shrink as well. I think you'll see a couple of less SMG-1s in the establishment of the bureaucracy and a much, much diminished advocacy brief being carried by government, and that's a shame. This is not the time to be doing that.

**Mr Grandmaître:** You're also qualified as a bunch of bureaucrats spending \$18 million.

**Mr Reville:** Yes. That was very hurtful. You should see me carrying the boxes around that place.

**Mr Grandmaître:** What are your thoughts on that kind of comment from the minister?

**Mr Reville:** It's a political shot. Obviously, if you want to get somebody mad at somebody, you call them a bureaucrat these days. There isn't anything bureaucratic about the commission. Our rights advisers work out of their houses. Their offices are on their belts. There are no bricks and mortar. When we have a contentious issues meeting at the commission, there aren't 40 people at it, I can tell you.

**Mrs Caplan:** Is there any time left?

**The Chair:** You've got one minute. I'll time you.

**Mr Reville:** It's good to see you, Mrs Caplan.

**Mrs Caplan:** Nice to see you, David. You know that while there have been things we've agreed with over the years, there have also been things we've disagreed with.

**Mr Reville:** It's too bad this is one of them.

**Mrs Caplan:** We know this government is intent on dismantling the commission as it exists, and the advice you've given today as to other options will prove helpful as they go through their focus groups and stuff.

**Mr Reville:** I hope so.

**Mrs Caplan:** Have you been involved with the—

**Mr Reville:** Yes. We were very happy to share our views. We thought the approach the government was taking was extremely narrow, boring and old-fashioned.

**Mrs Caplan:** As a former member of this House, no one would ever have criticized you for not being outspoken.

**Mr Reville:** That would be good.

**Mrs Caplan:** It's nice to see that your reputation is intact.

**Mr Reville:** Also, if I may say, it's nice to know that you believe government should do something about advocacy, and I hope you get a chance to tell the committee what you think that is.

**The Chair:** Thank you. We'll be receiving your proposal and the committee will consider it, I assume.

**Mr Reville:** I hope you do have it.

**The Chair:** I think we do, yes.

1400

#### MARILYN HEINTZ

**Ms Marilyn Heintz:** Good afternoon, members of the committee. I am Marilyn Heintz, and I'm here as an advocate and as a person who strongly believes that section 1 of this bill should be abolished. As far as I am concerned, I would like to inform you that what you are doing is putting the handicapped back instead of forward in society. That is what you are doing by bringing in this particular part of Bill 19.

My friends have told me that when they were growing up, they were always kept hidden in their homes; you never saw them in their community. Some of my friends were sterilized without having a choice. There were other choices where they wanted to live and work. I wish you would consider the handicapped and leave this act alone.

As the Advocacy Act states: "Being deprived of the freedom to make choices and decisions is one thing. Wilful exploitation, neglect and abuse of vulnerable and disabled persons is another. Yet for some elderly and disabled persons, that too is an everyday reality." Others, while quite capable of making their own choices and decisions, have been denied the opportunity to do so because they are unable to communicate in ways that are easily understood by others.

The main purpose of this Advocacy Act is to contribute to the empowerment of vulnerable persons and to promote respect of their rights, freedoms, autonomy and dignity. Although the word "empowerment" has come to be associated with a variety of movements, it means different things to different people. Some view it as a process, others as a state of mind.

Empowerment is about changing attitudes. If people with disabilities are to become empowered, society as a whole, and those who treat and care for them in particular, must begin to focus on their capabilities rather than their deficits. The only words I would change are "capabilities" to "abilities," and "deficits" to "disabilities."

If vulnerable people are to have control over their own lives, they must know what their rights and entitlements are. They must have real options and alternatives; otherwise choice is meaningless. What are our rights if you pass Bill 19? Can you guarantee that we will not lose our rights? I do not believe that is what you intend to do. If the handicapped do not have a family to take responsibility for them, who will do it?

Thank you for giving me the opportunity to appear before your committee. If I get a question I can't answer, I could probably find out who the members are and give you the answer eventually.

**The Chair:** Let's just see if you can answer them and how detailed they'll be.

**Mrs Johns:** Thank you for making your presentation today. A number of different issues have come up with respect to Bill 19. You focused on section 1 right now as you were talking. I want to deal with the consent to treatment. I know that's probably not an issue you've read, but I want to ask you, as you're dealing with People First—I see that you're the president of People First.

**Ms Heintz:** I am in Burlington, but People First has been disbanded in Burlington. I do talk with People First of Toronto and communicate with them every so often.

**Mrs Johns:** I want to talk about people receiving rights: their ability to receive rights and how they receive rights. I know that with People First that is an issue that's important to be able to talk to people about. Have you got any vision about how rights were provided in the past, how well that process worked, and any recommendations for what we should do in the future?

**Ms Heintz:** No, I don't. Would you like me to find the answer?

**Mrs Johns:** No, that's okay. People First may be coming in at a different time, so I'll ask again at another time, if that's okay.

**Mr David Ramsay (Timiskaming):** Thank you, Marilyn, for coming. Could you relate to us how the establishment of the Advocacy Commission influenced your life and had impact on your activities? How did it on a day-to-day basis do that?

**Ms Heintz:** I have a mother who's in a nursing home in Milton and I can't get to see her. But every so often the Advocacy Commission used to send me interesting issues. They sent me a paper about this committee coming up and that's why I answered it. I thought it's important for me to tell my story to you people.

**Mr Grandmaitre:** How did you get involved with People First?

**Ms Heintz:** When I first got married, my husband and I went to a conference in Toronto, and we got to know it through there. I worked with the handicapped and Arc Industries in Burlington, and I became president of People First Burlington until it folded.

**Mr Grandmaitre:** How did the Advocacy Act help you personally?

**Ms Heintz:** I find it gives me—

**Mr Grandmaitre:** Security?

**Ms Heintz:** Yes, it does.

**Mrs Boyd:** In the paper you've attached to your presentation, Marilyn, you talk a bit about having been a fortunate person in your circumstances because you had parents who were good advocates and who worked on your behalf. But many of the people who are members of People First either did not know their parents because they were institutionalized, often, from birth or had foster parents or did not have that kind of support. You've talked to a lot of these folks and you know that their issues are even more serious than the ones you've talked to us about in terms of their feeling helpless and feeling as though they weren't being empowered to make decisions themselves.

I know it's not appropriate for you to talk about any particular story that would be identifiable, but I wonder if you'd talk a little about how this whole notion of advocacy and rights advice within the group of people



you work with in People First actually impacts on people's lives. What would be different for people if there were advocates on whom they could call if they felt they were being mistreated? What would be different if, when they were in a medical situation, they could call upon someone to explain exactly what the decision was going to be about?

**Ms Heintz:** As you just said, Marion, about explaining, I think it's good that we have advocates. I had a girlfriend—and I talked to Mr Doyle about this a couple of months ago—who was critically ill. She's diabetic, and she had taken water pills; it reversed the reaction and she ended up with congestive heart failure. She's all right today, thank heavens, but I coached her as an advocate. I explained to her what the government is intending to do with this bill, because she didn't understand.

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**Mrs Boyd:** So that information flow is a big part of advocacy work.

**Ms Heintz:** Yes.

**Mrs Boyd:** Particularly if you're faced with a decision, it's important to know what your rights are. Very often, if you're a vulnerable person, you may be presented with choices, but they may be presented in such a way that you don't get a sense that you have the right to choose something different from what the person wants you to choose.

**Ms Heintz:** Yes, exactly.

**Mrs Boyd:** We find that's true a lot, particularly for people who are in institutions or are in workplaces that are specifically geared to work with those who have disabilities—may be very kindly met, but also have pressures on them.

One of the best examples I can remember is a situation in a vocational rehab workshop. Although the idea was to get people job-ready to go out in the world, because the workshop had to make a certain amount of profit there was a bit of a conflict there. People weren't really understanding that they had the right to leave; they were being told how important they were to raising the money. Does that happen a lot?

**Ms Heintz:** Yes, it does.

**Mrs Boyd:** I thought perhaps it did.

**Mr Marchese:** Ms Heintz, I want to make a quick point that maybe you have a reaction to. Mr Reville talked about a proposal that would only cost \$3 million as opposed to—

**Ms Heintz:** I have talked to him about that, briefly over the phone.

**Mr Marchese:** He said the objectives of this non-profit corporation would be to do community development, to do education and training, and also to deal with systemic problems. If this government can't even accept this proposal as a very minimal proposal to deal with issues that otherwise, in my view, would never be dealt with, we're not really doing very much out there, because no one out there is going to take on the job overall or generally to do these three things: community development, education and training, systemic problems. Do you have a sense of that?

**Ms Heintz:** I agree with what you said. I talked to David briefly yesterday afternoon about this plan, and as

a disabled advocate, I wholeheartedly support it. At least, you're keeping the people out of the institutions then putting them back in the institutions.

**Mr Gary L. Leadston (Kitchener-Wilmot):** Marilyn, I appreciate you coming out this afternoon.

**Ms Heintz:** I came on my own. I was supposed to be with a bunch of advocates from Burlington, but they chickened out.

**Mr Leadston:** You're doing a remarkable job, and thank you very much for coming. One thing I'm rather puzzled about in your comments. You said your husband and you were unable to visit your mother, who's in a nursing home. Could you clarify?

**Ms Heintz:** Transportation. My mom is in Milton. I went with my dad last Sunday, and that's the only way I could get to and from Milton.

**Mr Leadston:** I see. It's the obstacle of being transported—

**Ms Heintz:** I'd probably have to go from Burlington to Toronto and then backtrack to Milton to get to see her.

**Mr Leadston:** Thanks for clarifying that.

**Mrs Boyd:** There are a number of other groups from People First and from PUSH—a "sister" group that deals with similar matters but has a different kind of focus—that will be coming in front of us. The idea, I gather, of People First is to offer mutual support to one another to really regard yourselves as independent people, people who can make your own choices and so on. That sort of self-advocacy is hard to learn, isn't it, when you haven't had an example of it?

**Ms Heintz:** Yes.

**Mrs Boyd:** So the idea of this non-profit corporation that would offer some of the community development support for that would be very important. You said that your Burlington group disbanded.

**Ms Heintz:** Yes, it did.

**Mrs Boyd:** Did you have lack of support?

**Ms Heintz:** Yes, we did.

**Mrs Boyd:** That was your problem?

**Ms Heintz:** We talked about the Education Act at one time, and we had about 10 members, and it just folded from there. We hope to get it started up again. I work with a girlfriend who's critically ill, who's got diabetes. Now I help her out. I go as an advocate to her group.

**Mrs Boyd:** But for people who have disabilities, it really is important to have some way in which they can get that ongoing support and encouragement to keep up the work, because sometimes it feels very lonely and isolating, doesn't it, just to be talking to yourselves?

**Ms Heintz:** Yes.

**The Chair:** If there are no other questions, Ms Heintz, I thank you for taking the trouble to attend before us.

#### NIAGARA MENTAL HEALTH SURVIVORS NETWORK

**The Chair:** The Niagara Mental Health Survivors Network, Angela Browne.

**Ms Angela Browne:** I want to thank the standing committee on administration of justice for providing me with an opportunity to speak to you today. I feel particularly honoured to be your guest today as your government struggles with a number of very vital and very complex



issues and while its resources are becoming increasingly limited. You've got a tough role and I don't envy you.

My name is Angela Browne. I'm speaking as the executive director of the Niagara Mental Health Survivors Network. We're a voluntary group of people who have received mental health treatment and their families. Our membership includes approximately 80 persons who have been treated in the past for mental health problems and about 25 others who are family members or individuals who just have an interest in what we do.

In the past three years, the organization has transformed itself from a self-help, peer support focus to one that seeks to address solutions in three primary areas: economic development, where we try to do true economic development to form businesses that are actually going to become self-sufficient and pay people and get them off assistance; training and knowledge development, where people can find out more about different issues—for example, the law that's before us—and can figure out what's happening and what it means, that sort of thing; and human rights advocacy. We do a lot of this on an individual basis, where people come in, they have trouble with income maintenance or they have trouble with housing. We work with them, get it straightened up, help them get back.

So in the past two years, much of our work has been focused on conducting an employment barriers needs assessment and reporting on the proposed federal social security reforms and their potential impact on the people we work with and their families. Particularly, as you've seen, less government dollars come down from the feds. How are we going to deal with it at the provincial level?

In the last year or so, we provided input into a diversity of topics concerning our membership, ranging from systemic advocacy, community economic development and mental health reform to recent proposals for a new income support program for seniors and people with disabilities. We have an interest in this particular bill, given our membership's interest in these important issues and how they impact on human rights, how they impact on our ability to maintain the right to choose and how they impact on our move to self-determination.

1420

First, I want to state that in our membership we have many people who can be considered at times vulnerable, and this is within the context of your legislation, Bill 19. Second, many of these vulnerable people lack even the most basic information about their rights. They're frequently calling in and asking me: "What do I do? What is this about? What does this letter mean?" They can read it, but they don't know what it means, what to do about it. There's a sense that they need somebody there to work with them work through things. Third, this vulnerability is often compounded by social, economic and related mental health issues that make it difficult for people with mental health conditions to find out about, use and assert their rights.

In this presentation today, I want to touch upon some of the specifics of the bill, but most of all propose alternatives to ensure that vulnerable people could learn about and assert their self-determination, albeit very much in a cost-effective manner.

The first part of my comments relates to the repeal of the Advocacy Act, 1992, which will result in disbanding of the commission and removal of rights adviser and advocate portions of both the Substitute Decisions Act and the Consent to Treatment Act, now the Health Care Consent Act, I presume. Certainly, the concept of advocacy is not new to government. In response to allegations of deaths and rights violations taking place inside the provincial psychiatric institutes, the then provincial government moved quickly to institute the Psychiatric Patient Advocate Office under the Ministry of Health. With an aging population, there are increasing concerns about the quality of care older people are receiving in nursing homes, and in many cases in their families, who are often raising children themselves and paying down a mortgage. These families are unprepared for the responsibility yet feel obligated to maintain the elderly family members in the community instead of a nursing home.

With the push towards deinstitutionalization, there's an increasing amount of pressure on families and community-based services to provide the supports necessary to meet the basic needs of vulnerable people while attempting to encourage self-determination at the same time. With these growing pressures, the idea of non-legal advocacy continued to receive formal recognition from all three political parties and all three successions of government.

In 1986, the late Father Sean O'Sullivan was appointed to conduct a review of independent advocacy for vulnerable adults living in institutional care settings in the community. The then Attorney General appointed him to review that and to come up with some recommendations for an independent system of advocacy. A few years later an inquest was called into the death of Joseph Kendall, a resident at Cedar Glen Boarding Home, which was located in Uptergrove, a tiny community near Barrie, Ontario. As a result of this inquest, a public inquiry into regulated residential accommodations similar to Cedar Glen was called, and headed by Professor Ernie Lightman.

Problems identified as issues with Cedar Glen Boarding Home were found to be widespread, yet these homes continued to house our most vulnerable people in the community. As the horrors of Cedar Glen were investigated, our community learned about allegations against one of its own boarding homes by two former employees. Through informal channels, I learned that a man was suffering the early stages of a heart attack and that he approached the owners for help in getting him to the hospital. They told him to take a bus. What happened? Shortly thereafter I heard that the guy later died in hospital of congestive heart failure. He was only in his early 50s. That's not terribly old. Eventually, the former government passed Bill 74, the Advocacy Act, which established a commission to address these issues at both an individual and systemic level, these issues which still continue today.

Because of the vulnerability of people these acts deal with, it is the position of our members that some form of rights advice remain intact to ensure the rights of vulnerable people will stay protected. We have found through our own community-based consultations that most of the



people we work with are unaware of their rights. Many of them don't even know that they can work when they're on disability. Many of them don't know their rights if they're a tenant, don't know their rights if they're in a boarding house.

The effect of the Health Care Consent Act and its predecessor, the Consent to Treatment Act, is that they facilitate treatment processes while attempting to strike a balance of rights protection. Our question about this would be that if rights advisers other than those already mandated under the Mental Health Act are not available, the vulnerable people, not knowing their rights, can become susceptible to certain kinds of abuse. They're not going to know the act. They haven't read it. They don't do the work that I do. So I don't know how they're going to figure out about what they can do if some doctor tells them they're not capable of making a decision.

Recognizing the financial position of the province, we probably would recommend against building another \$18-million Advocacy Commission. We don't think that's a cost-effective way of doing it. But instead we'd recommend a closer examination of how existing funded and volunteer structures could be better coordinated to do this type of work. For example, there's already a structure that remains in place in the 10 provincial psychiatric hospitals. There's a rights adviser program for provincial psychiatric inmates facing certification. There's community legal clinics that provide legal education and support to vulnerable people facing evictions, Small Claims Court and other civil matters.

The Niagara Mental Health Survivors Network has provided assistance over the years to a number of individuals who had difficulty accessing services they need. We've also been around to provide non-legal advocacy services: take them to the doctor's, take them to the various places, make sure they could get what they need and so forth. For example, we might help members write letters to help them access their psychiatric records. We might accompany them to a hearing. We also support people who are tenants in boarding homes and so forth. We also maintain an up-to-date library on the latest legislation impacting on our members as well as various resources available to help them deal with problems.

We anticipate that an effective coordination of these existing resources would not only be relatively inexpensive, locally driven and flexible, according to how people's needs change, but would provide an excellent source for volunteer as well as paid work experience. While we do support volunteer advocacy, we take the position that there must be some paid staff to do some of the coordination function, but nowhere near where we're going to hire 5,000 people.

Our specific comments on Bill 19:

(1) We're particularly pleased with the clear definition of "informed consent." Finally somebody decided to put this on paper and say this is it. However, if a health care practitioner doesn't follow this procedure, are there any penalties? The difficulty mental health survivors often encounter is a lack of informed consent when they're given psychiatric care. Very few survivors are ever given full information on the risks and side effects of medication and other treatments. As a result, we are finding

people who believe they might never have never consented if they'd actually known what the side effects of the drugs were.

(2) We support the presumption of capacity to grant a power of attorney. This makes it easier for individuals who may have very minimal capacity to make some self-determination. We also support a person deemed incapable continuing to have some role in his or her care throughout the capacity determination process and appointment process and while the substitute decision-makers make a decision, so that they could express what they need or what they feel they want and the person would have to kind of listen to them as part of their process for making decisions.

(3) We support placing some responsibility on the part of the person refusing or consenting to treatment on another person's behalf to ensure that certain guidelines are maintained to ensure the individual's preferences are respected where they're known. We also support having a clear definition of "best interests," which includes the requirement of taking into consideration a person's wishes they had expressed before they became incompetent, their values and any current expressed wishes where they could be ascertained.

(4) We support the notion that in many instances it will be made easier for physicians to obtain the required consent from the patient to provide needed services. This gives a physician flexibility, and that's fine. However, when a patient is giving their consent, this should be explained to them to ensure that the patient understands what the scope of their consent they give entails and what the physician can do to them as a result of giving them that consent.

(5) We have some concern about the section outlining items that are not deemed to be treatment for the purposes of the act. There are a lot of openings here. This opens the doors to individuals being subjected to various tests, assessments and examinations as well as admission to a hospital or other facility. Additional procedures that will no longer be deemed to be treatments could be included in the regulations. This provides a lot of discretion. Our concern is that only procedures deemed to be treatment will require informed consent prior to carrying them out, other than in emergency situations. What about procedures not deemed to be treatment? Are people at risk of receiving unwanted medical intervention of any kind? Many types of examination can be considered invasive by the individual, regardless of no ill harm intended.

(6) The new act permits substitute decision-makers to consent to the use of shock as aversive conditioning. People with developmental handicaps have been protesting against this therapy for years. We feel there are plenty of alternatives to this type of therapy. Permitting substitute decision-makers to consent to this on another's behalf may encourage the use of the treatment beyond what is considered necessary. I see that as a step back, and I think what we need to do instead is maybe to explore some of the alternatives first with the parents and with the people who are dealing with people with developmental handicaps and perhaps require that they utilize



these channels first before they go into aversive conditioning.

We are concerned about what appear to be increased powers given to practitioners in administering treatment under certain circumstances. The act clearly outlines the criteria for decision-making for a substitute decision-maker. If a practitioner believes that the substitute decision-maker did not follow this procedure—which may be difficult to tell; it's mostly a matter of thought process—there are always ways the refusal of the substitute decision-maker can be overruled.

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We feel this power should only be permissible in the event of an emergency. In emergencies you can always have flexibility because somebody's going to need the help now, so you've got to give it to them. But the new act permits the physician to apply to the board regarding a substitute decision-maker's refusal even in non-emergency situations. If they feel the substitute decision-maker did not follow a decision-making process, which is again difficult to tell, the substitute decision-maker may have lost his right to act on the other's behalf.

That's not fair. I think there have got to be a few more guidelines there. There's got to be something that's not as arbitrary to determine this so that people can find out what's going on and make sure the people are following the directions. I can understand and appreciate why you might want to have that in there, but at the same time we want to make sure it doesn't move too far the other way, so in case somebody really is following the person's directions, that we're not going to have his rights overruled.

Protection from liability for practitioners and substitute decision-makers is extended in the proposed act. Before, the protection only applied to administration of treatments, from what I understand. Now it applies to decisions regarding admission of the person deemed incapable to a hospital or facility. Grounds for such a decision are not clearly established in the act, whereas a person could be forcibly confined, under the Mental Health Act, for 72 hours for an assessment if they're believed to be a danger to themselves or others. Do the same criteria apply under these circumstances? Maybe a clarification about what circumstances this can occur under.

We have concerns that in some cases one board member may constitute a quorum for the purposes of administering the act. I guess people who are experienced or have specific skills or something can act alone. In addition, there are proposed changes that will permit practitioners who may have had that person they are dealing with as a client or a patient five years ago or more than five years ago—there's a problem with that. There is still perception, and perception is reality here, if there could be a conflict of interest. We feel that the person needs to make the decision at arm's length and that there needs to be more than one body there hearing it. There needs to be more than one set of ears listening to it. The traditional quorum of three is fine.

We also like the mix of people, so that you have some expert and some non-expert people. It gives a good mix, a good representation from, say, the psychiatric, the legal community and laypersons. Besides that, it's cheaper too

when you have the laypersons because you don't have to pay them as much to come in.

In summary, our organization favours an approach that supports self-determination, maximizes choices for the individual and gives less power to practitioners to impose treatments to an individual that he may not want. Please know that to psychiatric survivors, imposed treatments are a major issue with the group. We believe that any piece of legislation or government policy that makes it easier for physicians or psychiatrists to force treatments on more people—some people find this frightening and intimidating.

What we find is that if treatment is given voluntarily and full, informed consent is given, people are going to comply with their treatment. They're to be going to be working with the doctors. But if it's brought on to them forcibly, they're going to be less likely wanting to work with the doctors, so you're going to have more problems with compliance that way. They'll find every way they can to fight it, and that's no good. That's no good. It's not conducive to the person's wellness and not conducive to the doctor or anybody.

Conversely, where treatment is cooperative, where people give full, informed consent, they have a choice, and whether through themselves or through a substitute decision-maker, they would be able to have a good relationship and be able to maximize their health and maximize their options.

Thank you for allowing us this opportunity to provide our comments on this bill. We open the floor to any of your questions.

**Mrs Caplan:** Thank you for an excellent brief. It's nice to see you again. You were out in Niagara when we were there on Bill 26.

**Ms Browne:** Oh, yes. I get around.

**Mrs Caplan:** You have raised an issue that we haven't had raised before: the issue of protection from liability for both practitioners and substitute decision-makers. No one's raised that before the committee and it's something that I have a concern about. On the one hand, people who act as assessors or evaluators under the bill have no obligation to tell a person when they've been deemed incapable, and treatment can occur and they are free from any liability. In other words, you can't take them to court if later on you find that they acted in a way that was contrary to your wishes. You can't argue, "I was never told." I just think that's fundamentally wrong.

I thank you for raising that because I'm not sure people understand fully the implications of that. You might want to go into that, just in the few minutes we have, a little bit more as to how you see that working.

**Ms Browne:** Yes. There is a legal implication to that. You're dealing also with Charter of Rights issues. Some of the stuff could be challenged under the Charter of Rights. You would like to make sure that people are informed of what is happening and that they're informed of their rights. Removing the rights advice portion of this creates problems. It doesn't have to be through an advocacy commission. It could be something similar to the rights adviser programs in psychiatric hospitals.

**Mrs Caplan:** It's interesting that you mention that, because of course the psychiatric hospitals are covered by



the Mental Health Act and they have rights advisers and advocates.

**Ms Browne:** Yes.

**Mrs Caplan:** That's the Psychiatric Patient Advocate Office. It's been existing now for a number of years, we heard 20 years. They don't have jurisdiction over the community hospitals, and this bill doesn't give them that jurisdiction.

**Ms Browne:** No. Even the psychiatric courts.

**Mrs Caplan:** So people who are in a psychiatric hospital have different rights than people in psych programs in general hospitals. I think that's an important distinction.

I agree with you when you say that we can see a new model for advocacy services and that it doesn't have to be as expensive.

**Ms Browne:** A lot cheaper.

**Mrs Caplan:** Would you like to tell us how you see that working?

**Ms Browne:** Yes. You see, there are advocacy services already taking place at the community levels. They're funded by the government, they're funded by the United Way, they're self-funded; there are various ways. Some of them are just volunteer groups. But find a way to tap into them; find out what's going on. Perhaps there could be a way of coordinating these services so that they could be better delivered, and more effectively.

**Mrs Caplan:** I think the coordination is key, but I also think some quality standards to make sure that the training is consistent.

**Ms Browne:** Yes. Some kind of training to make sure that the person who's going to be your rights advisor knows what they're advising people, to make sure they know the law, to make sure they know how to deal with the people. You have to have minimum standards and minimum qualifications there. You can't just have anybody go in and do that.

**Mrs Caplan:** It's coordination that's the key.

**Ms Browne:** Yes.

**Mrs Caplan:** I just want to thank you for a thoughtful brief and also for raising the issue about the fact that people who find someone incapable and consent to the treatment on their behalf, both the provider of the treatment and the persons who consented on the person's behalf, cannot be challenged. Under circumstances, if you're going to give that protection to them, which in some cases may be justified—

**Ms Browne:** Very much so.

**Mrs Caplan:** I'm not saying it's not justified; the concern I have is that at least they should have the obligation to let the person know that he has been found incapable and that he has a right to appeal that decision.

**Ms Browne:** Yes, exactly. Particularly in the event of an emergency, you want to have them protected. You don't want to have them in a situation where they're risking a lawsuit because they're treating somebody. They have to have that protection. I'm not saying to remove the protection. What I'm saying is, clarify it; make sure the person knows what's going on; make sure the person knows what he can do to challenge it if he felt he needed to challenge it.

Most of the time—they had studies; they had lots of studies done where they did that with psychiatric

patients—very few of them ever challenged their commitment. Most of them just basically went along with it. So putting something like that in place is not going to turn into a big, horrendous, expensive, bureaucratic nightmare. I'm sure it won't. I'm sure that this small change will do a lot of good for the people.

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**Mr Marchese:** Ms Browne, I'm one of those who believe that what this government has done with respect to the repealing of the Advocacy Act is wrong and irresponsible. I really believe that if they felt \$18 million was just too much, they could have cut that down and dealt with some of the concerns they might have had in that way, as opposed to simply repealing it. Having nothing in its place and looking at what they might do later on, after they have repealed it, I think is just reprehensible.

Mr Reville said that he has proposed a \$3-million non-profit corporation that would deal with three objectives: that is, doing community development, education and training and also dealing with systemic kinds of issues, which the commission started to do and would have dealt with but in this proposal obviously would be—

**Ms Browne:** Would be repealed, yes.

**Mr Marchese:** —in a smaller kind of form.

My sense is that this would provide the coordination that is necessary and that it would provide presumably the kinds of quality standards that Mrs Caplan is getting at. That's what they would have dealt with with the commission; this is what they would be doing. Is this something that you agree with, or do you have suggestions other than that?

**Ms Browne:** I feel uncomfortable with anything centralized. I sort of get scared because it smacks of bureaucracy. I like things local, and then you kind of work yourself in the grass roots. That way, when you have a local determination, you're better off and you're dealing with the folks who are already doing it in the community. Many times, if you have a provincial corporation, it might be nice to have everything done there, all the standards done there, all the training done there, but the problem is that many times the people who are already doing it in the community are being missed out, you don't know what's going on and you're not tying those pieces together when you have that. So this is why I think it should come from the community. I believe there are some very effective ways that can be done.

**Mr Marchese:** I know Mr Johnson agrees with you, but I have some questions about that. Part of the problem is that when you don't coordinate these services, everybody's doing their own thing. This government is providing much less money than ever before, which means they have a lot less to do.

**Ms Browne:** Obviously.

**Mr Marchese:** The people on that commission came from the community. It's not as if these people are abstractions. They come from the very services you're talking about, so it's not as if we're operating in a vacuum.

If you're not doing that and you have a lot less money, who coordinates that? The various little agencies? Or do you just talk to them, saying, "Please do that"? Or what

kind of direction would you give to all these little groups across the province?

**Ms Browne:** The thing is, if you coordinate it provincially, you're still not looking after local needs. Different locales have different needs, different ways of doing things. Niagara might want to have more systemic advocacy; there might be something dealing with the nursing homes scene, whereas in Toronto it's more important for people to know the psychiatric rights and send the rights advisers up. There need to be some assessments done locally, and figure out where it does. It would be funded provincially in terms of funding coordination, but in terms of the actual work, where people are determining what's needed, how the agencies work together—

**Mrs Boyd:** But you're seeing it on a cross-disability basis rather than just—

**Ms Browne:** Yes, and seniors as well.

**Mrs Boyd:** Rather than all the separated advocacy work.

**Ms Browne:** Yes, it would have to be a cross-disability of some sort. If you start going with just the psychiatric, you're going to end up with what she was bringing up about the PPAO and how the psychiatric survivors get help in the hospitals. But if your mother goes in the hospital with Alzheimer's, she doesn't have the same rights advice as someone in the Queen Street Mental Health Centre, and that disparity needs to be addressed; not the other way around, but we need to have the rights given to your mother in the nursing home too.

**Mr Tilson:** I can't believe that you won't get a call from the ministry with respect to some of the suggestions you've made, particularly your comment in your introductory remarks about the use of volunteer groups, where you recommend a close examination of how existing funded and volunteer structures can be better coordinated for this type of work.

I guess this is following along the line of one of the earlier questions, but just on the issue of age—our population is getting older. In fact, some report just came out and talked about how the baby-boomers are getting fatter and gosh knows what all. It is an issue that we certainly need to anticipate in the years ahead, that we're going to have an older population—just on that topic alone.

The main comment you made that interested me was that everyone does have different needs, yet we've only got so many resources to do these things, and we're going to count on volunteer groups. So I certainly encourage you to keep going with the message that you've recommended to make use of these volunteer groups.

The question I have is just on that topic. Your organization is basically a volunteer group?

**Ms Browne:** The thing is, once in a while we do get one paid person—me. But I think there should be at least a couple of people paid. The thing is, it's very hard to coordinate volunteers who are just volunteers. It was tried and it doesn't work with our group. In some groups they might have been able to do that. It really depends on the type of group, the type of cultural environment you have, whatever.

**Mr Tilson:** You indicate that there are a number of volunteer groups across the province that you communicate with.

**Ms Browne:** We get called upon. We get calls from various groups, we get calls from the hospitals, we get calls from other local groups, asking us to look into certain situations, and we do. Look, my time is valuable too and there has to be some way of being able to balance it off. Yes, we do need the volunteers and we've got to develop the volunteers, because basically, if we pay everybody, our treasury will be broke. We don't have the money in the treasury. But when we pay some people who are going to be effectively doing a lot of the complex matters and training the volunteers to do some of the things where people just need somebody to be by their side when they're doing something, then these things could be effectively coordinated in these ways.

**Mr Tilson:** Keep up the good work. Thank you.

**Mrs Johns:** I wanted to ask you about section 9 in your report. That's about the one-person boards that we were talking about.

**Ms Browne:** Oh, yes. I saw you nodding your head when I was saying that.

**Mrs Johns:** Well, you make some very good points. One of the reasons we came to a one-person board was the timeliness of being able to react quickly to demands, and especially in rural and northern Ontario, bringing three people together. How strongly do you feel about the one-person board? Can you see the two sides, the need to act quickly in some cases for the one-person board, if we make that person a person who has expertise in the area and does not have conflict of interest? Can you see that situation or do you think in every case it's not appropriate?

**Ms Browne:** The problem is you start a precedent, get a one-person board in a place, and that person's future is going to be in this one person's hands. It sounds scary.

**Mrs Johns:** So you'd want to see a lot of controls.

**Ms Browne:** Yes. Maybe about three sets of heads, three sets of ears listening to the presentation, and at least try to do something. Many times a person may be very much an expert in their field—and I do respect that a lot of these people have been doing this for years and are quite capable—but the thing is, what happens is people get very grounded in their own ideas about how things should be or their own culture or their own ideas about what's right and what's wrong and that sort of thing. You need to bounce it off someone else. Somebody else may have a different idea and say, "Oh, well, that person is just doing this because of this," or whatever. They might have a different idea about that person's background than other people.

There's no way that one person could possibly understand every single culture, every single personal issue with a large, very diverse group of vulnerable people. I know three people can't either, but we're looking at balancing this off, because you don't want to spend money on bringing 15 people together, nor do you want to have it so there's only one person. So I'd say probably three is a good balance.

**The Chair:** Thank you, Mrs Browne. We do appreciate, because we realize the amount of work that you have



put into this presentation, and your group, and we enjoy your practical approach to many of the concerns, whether we agree or not. Thank you very much.

**Mrs Caplan:** Let us know if the minister calls.

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### ROBERT WALSH

**The Chair:** Mr Robert Walsh. Mr Walsh, welcome. You have one half-hour, including all questions, so you can proceed with your presentation.

**Mr Robert Walsh:** Okay, thank you very much. Honourable members of Parliament, I would like to make an observation of something that I saw on the way coming in today. My wife is with me and we walked down University Avenue and we found two people who are homeless, I suspect, covered with blankets. It really caused me to think about a few things. On one hand, you would like to be able to take a person who is in that situation and say, "I'll make everything right for you." Then there is a saying, "Well, are we going to take away rights from this person?" We're living in a rights kind of way.

I have a few ideas and I'd like to express them. My name is Robert Walsh and I have schizophrenia. The last time I spoke at the assembly's committee on the administration of justice was in February 1992. I gained a great deal of support for a contract where I can have my health care providers reject my rejection of treatment when that rejection of treatment is due to paranoia, ideas of reference, psychosis, hallucinations. It turns out I was describing a Ulysses contract, but at that time it was quite new to us.

If during hospitalization I have a change of heart and do not wish to be hospitalized, I frequently know just what to say and just what not to say. To determine if I am still ill is difficult for health care providers, but my wife knows. This is not uncommon. I know of several people who, though ill, managed to get their discharge. A couple of these went home and committed suicide.

My first point is that even psychiatrists, with all of their training and diagnostic abilities, do fail. I know of two people who ended their lives while they were in our Homewood psychiatric hospital. One was an old lady about 63 and she took a large bottle of aspirin. I guess her stomach bled. She bled to death. The other was a girl who went home, took her medication, all of it, came back to hospital and asked my friend, "Please sit with me while I fall asleep." She died.

It's just amazing to me, when you look at the statistics of mental illness, the confusion that you people have to make a decision which is going to be able to be empowering for the most people.

I've been admitted to the hospital 15 times since I first became ill. In 1986 I was misdiagnosed during a three-month duration of hospitalization. I was totally diagnosed wrong, to the point where I was discharged and the capacity assessor's ability—even the psychiatrists fail—but my wife has always been right on the money. It's a difficult thing to know whom do you trust to see what's going on. I have to trust someone, a psychiatrist, a capacity assessor, a rights adviser, but my wife has been

doing these jobs since 1986. Even at that, she has not asked anything about my capacity. I trust and choose her to know where I am as far as my mental health is concerned. My wife is able to tell if I am well or just playing the part. Her insight is important, and having said that, she has not often been asked for her insight.

Stress causes me to relapse. I was hospitalized three weeks recently and I was in a locked unit for two of those three weeks. This was the most difficult hospitalization, but I was held against my will because a treatment team had determined that my suicide was impending.

My problem is that when we are ill we may avoid treatment due to fear or illness symptoms. Refusing help is very common with mental illness, but this government has considered that and has kept the Ulysses contract available for the power of attorney for personal care. This means that if I am ill, I should be treated, even against my will. That's great. However, the government has provisions for a capacity assessor who would assess the individual who is refusing treatment, thus disabling someone's Ulysses contract and their power of attorney. Treat me; if I refuse treatment, reject my rejection. I think that is the basic definition of a Ulysses clause and what has happened is, we have said, "What happens if someone takes advantage of this man and treats him, and he stays indefinitely?" or whatever. What happens if he's going through a rights problem? You have to have an option to make a decision to stay treated against your will if you're prone to rejecting help, or you make a contract where you do nothing and you keep the rights you have before legislated.

My friends who visited me at the last hospitalization said to me, and they have mental illnesses: "You look just fine. What was wrong?" I looked wonderful. My own friends, who are schizophrenics and manic depressives and whatever, looked at me while I was in the hospital, believing delusional things and being very ill, and commented that I looked well. The problem is, I have to trust someone who will know when I'm ill and when I'm well. I have to trust someone. To ask a person to put someone else in control over your life, you have to be able to trust that individual. Once you have come to know a person you can trust with your own reality, then you can perhaps set aside your own perspective and listen to what that person has to say, and probably would even agree to treatment.

If I'm ill and I refuse treatment and I'm suffering from the delusions and the psychosis and all of this, I don't want to sabotage my treatment; I want the Ulysses contract to stand as it was. A capacity assessor has assessed my ability, my rights have been advised by a rights adviser and I feel I've taken precautions enough and I understand what could happen if I lose control of myself and allow my wife to have control with our psychiatrist.

As I mentioned earlier, I once was diagnosed for three months with a bipolar disorder, the manic depressive illness, because I wasn't speaking about what was going through my mind. It's also interesting that the psychiatrists weren't really asking. My experience with psychiatrists is, they don't really want to know what the psychosis is; they just want to know whether it's present or not.

Perception is a problem. I could say something I believe, which I've done, and given it to my last psychiatrist, something of my religious beliefs. He read it and he said, "I can understand why you feel the way you do." The same work that I had written some five years earlier, the psychiatrist said to me, "You are a very ill man; we need you to stay in hospital and increase your medication." Nothing had changed, just someone else's perspective of what I was writing and saying. I say that because my wife, if she was asked, would know whether I am well or whether I'm not.

I'm concerned that it's a possibility to actually sabotage my own treatment by having a capacity assessor come and assess that I'm well enough to make a lot of personal decisions, but when it comes down to the fearful part that I have, about submitting myself to treatment, that's a separate thing altogether and I think it should be looked at. My wife, again, has always known and yet we don't ask the families. I have one perspective when I'm well and I have another perspective when I'm ill.

How can I sit here before you and tell you I want you to treat me against my will when I've never actually rejected treatment, except for once, because I had delusions that I was created eternally by God and no one could destroy me, not even a gun or a bullet or being beaten or anything like that. I had a delusion that allowed me to go into the psychiatric hospital, without really wanting to be there, just to prove that when they see I cannot be destroyed, then they will believe that I am someone to be listened to.

Of course, that's redeeming for me because it's a delusion that actually helps me accept treatment. A lot of people don't have a delusion like that. Their delusion is that when they go into the hospital someone's going to poison them and they're going to die.

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The alternatives are sometimes like two people who are sitting outside at Queen's Park, on University Avenue on the boulevard who are covered with blankets. Thankfully there was a big drive some time ago—it's still ongoing—to give blankets to the people who live on the street.

I'd also like to speak for 27,000 other Canadians who have been lost and have slipped through the cracks of the system by well-meaning thoughts and ideas. Those are 27,000 schizophrenics who have committed suicide or are committing suicide. One per cent of the population has schizophrenia and 10% of all of these kill themselves. I believe the main reason that happens is they haven't accepted the treatment or haven't accept the illness, believe they're very important and feel very important and walk around, and they're rejected by society and looked down upon, chased out of restaurants sometimes and what not.

I knew one guy who was very ill and he was banned from a number of different restaurants because he was really very dirty. I talked with his family a number of times and listened to their dilemma, how could they treat this man, he's living on the street. There wasn't any way unless he broke the law. Well, he did break the law and he did go to court and he was requested to take psychia-

tric treatment. The man is now married and has a good job and is keeping on.

Rights: My rights, your rights or someone else's rights. If you can't allow me to have a Ulysses contract where I can have my caregivers reject my rejection of treatment when my rejection of treatment is due to my illness, then at least give me the right to waiver for three weeks a capacity assessor and cause my power of attorney to become validated upon assessment of a psychiatrist who my wife and I trust.

The psychiatrist could in turn contact the public guardian and trustee and say he's validated the power of attorney. Give me three weeks and hold me in hospital, allow me to be treated. Even I refuse help, treat me anyway. I will get better and I will thank God that someone has made a provision, so that way I don't end up 1 in 10 or 1 in 100 or 1 in 33% of all these different groups.

It kind of sounds funny to talk about this, my mental illness, when I haven't actually rejected help. But I have a son who is 16 and my concern is—I was very happy when the law was first put together with respect to the Ulysses contract. But my frustration is now. I know how my son thinks. My son is very headstrong and if I told him it was black, he would tell me it was white. There is no way he would be able to trust my perception or my wife's perception. If we had a Ulysses contract then it could be possible, if he rejects help, he'll become well again and then he'll realize what actually happened. You don't lose your memory of the things you believed; it's still there. When you become well you say, "Wow, I can't believe I believed that."

If I was writing a will it would be easy to take care of my property. No one would challenge my will, unless it seemed really bizarre. I understand the concern when it's a living person making a living decision, but I'm asking that we have the right to make these decisions.

If you choose not to make this contract, then you don't have any losses and you don't have any gains if you refuse to make this contract, but if you, however, do make this contract, possibly even before you became ill, you may be able to save yourself from a life on the street by being empowered. When you're in high school and educated, if you made this contract with a Ulysses contract within it, if you're suffering from mental illness, you will be treated in spite of your refusal and you will get better.

My one thing I would like to compare what I'm asking for to is maybe in other terms where it might be easier to understand. If your mother was fourth on the list for a heart transplant and she was paranoid of operations, if she had the ability to say, "I make this contract now, reject my rejection of the operation and let me go through this and let me become well if I can," you can kind of see that. Sure, if you're scared of the hospitalization and it's a physical thing and you're going to get treated and you might do better, yes, that sounds pretty good.

However, it always seems when we get into these grey areas that we all decide we've got to make everything blue or we've got to make everything green. Allow me to be empowered as I've asked to be empowered and allow someone else to make the decision not to do anything or



allow them to make another decision to waive the capacity assessment.

I'm very hopeful you will see that what I'm asking for is something that could be quite helpful for some people. I am quite nervous, but if you have any questions, I'd like to answer as I can.

**The Vice-Chair:** Thank you very much, Mr Walsh. We're going to entertain some questions now, if that's okay, and we're looking at about four minutes per caucus. We'll start with the NDP.

**Mrs Boyd:** Thank you very much for bringing up a number of issues that haven't been talked about here before. I stand to be corrected, but my understanding of the revisions in the act that's in front of us would be that it would provide for a kind of Ulysses contract, if you want to talk about it as that, within the power of attorney, so that you would under this act have the opportunity to name someone you trusted and that you could waive.

One of the conditions you could put into your power of attorney would be to waive the right to prevent your decision-making power to reject treatment under those circumstances, exactly as you've talked about. Now am I right? I see nods from those who—

**Mrs Caplan:** It would be nice if Hansard could record that the ministry's agreeing with Mrs Boyd.

**Mrs Boyd:** The ministry is agreeing that's the case, so I think the government's bill is trying to provide for the very real and very urgent problem you've brought forward. I think that was a result of some of the real concerns people have had, so that where that arrangement works well, where a person who has capacity at a time, as you have had, to understand that when you get into difficulty you may want to reject a treatment that otherwise you would have accepted, you can do that under a power of attorney.

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I suppose the problem is that a lot of people in your circumstances are not as fortunate as you are to have a person like your wife whom you can trust to that extent and so it really is the kind of provision that is there when you have someone you can trust. Many of the people you talked about with great empathy who may be all alone, who may be rejected out there on the street, who would similarly benefit may not have that kind of opportunity, and so trying to create a law that is going to provide that right to both of those individuals is somewhat difficult. It certainly puts an onus on the public guardian and trustee if they are to be the trustee in those circumstances.

**Mr Walsh:** I thank you for that information. I've been contacting the public guardian and trustee and presently my power of attorney is going to be registered soon, but I was advised by the people at the public guardian and trustee that if I did refuse help, they would send a capacity assessor to determine. Now if there's confusion there—which is why I'm here; I've got different information from different sources who really don't know what's happening. I really didn't want to lose that piece within the legislation.

**Mrs Boyd:** So one of the things we need to be doing as we go through clause-by-clause is making sure that through the wording and the understanding of the public guardian and trustee's office and really quite clearly

where someone has a trusted power of attorney for personal care, this is still possible. That's something that we really are grateful you have told us there's some confusion there. I think the intention clearly of the government was to allow that to continue, where there is a power of attorney.

**Mr Tilson:** Thank you very much for your comments. I think Mrs Boyd is correct. Probably when we do get into clause-by-clause, we can confirm some of the questions that are being raised. Section 32 I think is the pertinent section, which deals with the Ulysses contract issue and essentially waives rights; in other words, you are able to elect to waive your legal rights because you're the one who best knows what your needs are and there's nothing in the act which forces you to enter into any kind of arrangement.

I'm not going to take the time to read the section, because we'll do that in the last week, but the changes retain the key safeguards which ensure that the person is mentally capable when they sign their rights away and that they receive information about their rights and that they sign a form of acknowledgement at that time. The current requirements of the registration with the official guardian and public trustee and validation do not provide for any effective assurances, and that's what we're trying to do in the changes in this specific legislation. We believe that they only make it difficult for the attorney to take actions that the persons have asked them to take.

In your case, you've described your wife as someone you have trusted on it and that you would know your rights at that particular time and that you trust your wife with making decisions. She then wouldn't have to get it validated at a later date. I believe, if I interpreted what you were saying in your statements, that was your concern.

**Mr Walsh:** I'm very happy to hear that.

**Mrs Johns:** I'd like to add one thing to that. The Ulysses contract in the consent to treatment is section 22 and it also maintains what you're asking for in this statement too, so you may want to write that section down. I'll make sure you get a copy outside.

**Mr Walsh:** Thank you.

**Mrs Caplan:** I'd like to see if I can clarify this, but I'd also like to request that the ministry give you something in writing that clarifies it and clarifies it for us, because I see that there are two things here which could be a little confusing. The first is I believe section 22 under the health care consent, which does allow what's called an advance directive. You've been referring to it as a Ulysses contract. If it's not that section, I'd like to know what section it is.

You referred to 22 and I don't see it in that section, so if you could let me know what section it really is, that would be helpful. There's always been a provision—and it may not be here—under the Mental Health Act that allows an individual to have an advance directive for their wishes at a time when they become ill. Now I don't see that here, so I assume that remains in the Mental Health Act.

**Mrs Caplan:** If you look at 32, the problem that I see is this—and I think this is what you're referring to—power of attorney for personal care is only valid when

you are incompetent. It has to be written when you are deemed competent. So you write it when you're well and then you get sick and your wife has authority. But if you say, "I think I'm fine and I want to reject this treatment," there's a question as to whether or not you're competent, and that's where they send in the assessor, who may decide that you're competent.

I think that perhaps is the confusion that's out there as to whether or not the power of attorney has to be—you have to be determined to be incompetent. It may not be a problem if you're on an in-patient basis and you have been admitted to hospital of your own free will. They may determine that the power of attorney is valid. So I'd like some clarification, because I think you raise a good question, and I'd like to know specifically what sections in this act or in the Mental Health Act would apply.

I believe that your concern has been addressed and that you don't have to worry, but I think you should have it in writing to take home and show your wife and your doctor, so that if there is ever any question, that you'll have that. Also, I think it would be helpful to all of us if we had some clarification, because I know that there are the two separate avenues for how to ensure that an advance directive can be given. Power of attorney is only one of them. The Ulysses contract is the other.

The question I'd have for the ministry is, has there been any change in that that we should be aware of and why is the office of the guardian and trustee giving Mr Walsh the information that they have been giving him? Does this act change what is in the existing act to fix a problem that he was concerned about?

**Mr Walsh:** What you mentioned is what my concern is with the Ulysses contract if I refuse treatment. My concern is they will assess me for capacity and could very well find that I am quite capable of making all kinds of decisions, but the one that I can't make is the fear of submitting myself to hospital.

**Mrs Caplan:** That's right. And what you're saying is that in that situation you trust your wife and not an assessor.

**Mr Walsh:** In the situation, yes.

**Mrs Caplan:** Is there any way that you can ensure that your wife is the one who's listened to? I think that can happen. We've seen the ministry people nodding their heads, and we want to make sure that we're right and that you can have that confidence to know that nobody will be able to come in and overrule your wife, if that's who you have confidence in.

**The Vice-Chair:** Mrs Caplan, we're down to about three or four minutes, so we've got enough time for one more question from each caucus if you're interested.

**Mrs Caplan:** Maybe we could have clarification from the ministry. I'd give up my time to let them put it on the record.

**The Vice-Chair:** So we'll start with the third party again, if you wanted one quick question.

**Mrs Boyd:** We would like some clarification on this because we are going to hear this again. I think the Friends of Schizophrenics are going to be speaking to us. This is one of the consistent issues that they have raised, as to how to help people who, when they're capable, understand that they must have treatment and want it, and

then we get into this. So I think it's a fairly close issue, and certainly in the briefings that we had on the bill we got the full sense that the ministry was convinced that they had maintained that right, and certainly that was the intention.

If we can't get that assurance this afternoon, at least we all at the committee know that that's a major item for us to be dealing with in our clause-by-clause consideration, and we can ask Andrew and the people from the ministry to be sure that we have that clarification so that as we go clause-by-clause we can put those protections in for you and for many other people who have a similar concern.

**Mr Walsh:** Thank you.

**Mr Tilson:** I thought I'd expressed myself properly, but perhaps I haven't. This issue is probably a matter which should be dealt with in clause-by-clause, but I guess the question of having someone come forward now is, we don't want to jump in on someone else's time.

I have no problem requesting that the ministry at a later date provide something in writing for the purpose of the committee. It's my understanding the ministry has written Mr Walsh some time previously for his personal use, and I think it would be unfair of the committee to ask for that letter. Certainly as far as the power of attorney is concerned, if a person wants some form of validation, he or she can write that right into the document, and that's a matter of personal choice for that individual.

The questions being raised by my friends—I have no problem requesting the ministry at the appropriate time to provide something in writing for the committee.

1520

**The Vice-Chair:** Ms Caplan, you have one minute.

**Mrs Caplan:** Is there any possibility that the ministry would come forward now? Trudy? They're willing to take a minute.

**Mr Tilson:** I don't know what the timing is. I don't know how long that timing's going to take. I tried to condense it. Obviously, some questions have been raised. I certainly don't want to get into the time of other—

**Mrs Caplan:** In the time you've taken to talk, they could have answered the question.

**Mr Tilson:** I don't agree with that. I made a statement and you didn't think that was enough. I'm saying if you want a thorough presentation, we'll give it to you.

**Mrs Caplan:** All we're suggesting, David, is that a lot of people are going to have this same question. If the ministry can take a couple of minutes to clarify it—

**Mr Tilson:** I said we're going to give you what you want. You asked for it.

**Mrs Caplan:** If you don't do it until clause-by-clause—

**Mr Tilson:** We're going to give it to you in writing.

**Mrs Caplan:** It's ridiculous.

**Mr Tilson:** We're doing what you want.

**The Vice-Chair:** We are running approximately five minutes ahead of schedule, so if in fact ministry staff did want to do a quick two- or three-minute presentation to try to fill in some of those blanks, we can do that.

**Mrs Caplan:** It would be very helpful.



**The Vice-Chair:** We are through, Mr Robert Walsh, with your presentation. On behalf of the committee, I want to thank you very much.

**Mr Walsh:** Thank you.

**Ms Trudy Spinks:** Thank you, Mr Chair. I'll get on with it in the interests of time. I'm just going to explain what the Substitute Decisions Act, as amended, provides about the Ulysses contract, and Halyna from the Ministry of Health will tell you how that is buttressed and connected to the Health Care Consent Act.

At the present time, the Substitute Decisions Act allows people to make a special kind of power of attorney that waives in advance their rights. At the moment, in order to use that document, it requires a number of steps. It requires at the first instance, when it's signed, a capacity assessment by an assessor to make sure that the person understands what it is they're signing. It then requires registration with the public guardian and trustee's office. That is why Mr Walsh would have been told today that that is the law as it stands until such time as this bill may be passed.

So it starts with the capacity assessment, it is then registered and it stays in the register. If there is an onset of incapacity, a periodic onset of this, then currently a capacity assessor would be required to validate that power of attorney, in other words, to confirm that the person who had signed it had indeed become incapable, and that authority would only continue for as long as that person remained incapable. Then in order to revoke that validation, a further capacity assessment saying the person was capable would be necessary.

The amendments simplify that process. The document is retained, the mechanism is still there, the capacity assessment at the first instance which says that the person is capable is still required, but the additional steps of registration and validation will no longer be necessary.

**Mrs Caplan:** Is there still a requirement for a capacity assessment at the other end?

**Ms Spinks:** There's a requirement for a capacity assessment when it's initially signed and there is a requirement for a capacity assessment in order for the document to be revoked. In both instances it would have to find that the person's capable.

**Ms Halyna Perun:** And then the linkage from that is, as Mrs Johns referred to, section 22 on page 76 of the Health Care Consent Act with respect to an admission to a hospital. The same language as appears in the current section 19 of the Consent to Treatment Act is preserved, but the wording has been changed to reflect what's happening now under section 50 of the amendments to the Substitute Decisions Act. So basically, under subsection 22(2), if the incapable person is 16 years old or older and objects to being admitted to a psych facility for treatment, consent to his or her admission may be given only by his or her guardian or his or her attorney for personal care if the power of attorney contains a provision authorizing the attorney to do so and is effective under section 50 of the Substitute Decisions Act. That's the Ulysses contract. So it's preserved with the new wording.

Following from that, where a practitioner finds a person to be incapable of treatment, so it is the opinion

that the person is incapable of treatment he or she is proposing, and the substitute decider is under a power of attorney that is effective, again under section 50, that person has no right of review to the board because effectively while they were capable they waived that right of review. That is found in clause 30(1)(b) on page 80 of the Health Care Consent Act.

**Mrs Caplan:** Mr Walsh's concern is that he signed power of attorney, he's given it to his wife, he's concerned about the assessor coming in and finding him competent when his wife knows he's incompetent. Is there any way he could safeguard against that provision so the assessor would be required to listen to the wife? If he were to put something like that in the power of attorney to clarify that he instructs any assessors they must take the advice of his wife, would that do it?

**Ms Spinks:** There is a section which allows you to include in the power of attorney instructions or considerations you want the assessor to make in the amendments—

**Mrs Caplan:** So that would do it?

**Ms Spinks:** —will accomplish that.

**Mrs Caplan:** That should answer your concern, Mr Walsh. If you leave your address with the clerk, we can send you a copy of that Hansard.

**Mr Walsh:** Thank you very much.

**Mr Tilson:** I think we should clarify one point just so we understand what your comment was. At the time of treatment there's no need for an assessor to be there at that particular time. The only time the assessor's going to be there is at the outset or at the time of revocation, if there is revocation. Is that what you meant?

**Mrs Caplan:** His concern is about revocation, if he doesn't want it revoked. That's the concern.

**Mrs Boyd:** Even though he might ask for it.

**Mrs Caplan:** Even though he may ask for it to be revoked, he's going to say, "I'm competent, revoke this"—

**Mr Tilson:** Which could come at treatment.

**Mrs Caplan:** At the point of treatment, he's going to say, "No, no, I changed my mind, I'm fine." An assessor comes in, and what he's saying is, "Listen to my wife, don't listen to me."

**Mr Tilson:** So the answer is to put it in the agreement.

**Mrs Caplan:** Put it into the power of attorney under the instructions.

NAOMI MORI  
AARON SHELBOURNE

**The Chair:** We'll proceed to the next presentation, Naomi Mori. Thank you for attending at the committee, and you have one half-hour starting from now.

**Ms Naomi Mori:** Thank you. I've prepared a written script. I apologize for reading, but I thought it would help keep me focused and move things along.

I do want to thank you, first of all, for the opportunity to be here today. I'd like to start by telling you a little about my background relevant to Bill 19, then I'd like to focus on my perspective on the proposed legislation based on, I have to admit, a cursory knowledge of it. I'd like to follow that with a few case studies, if you will,

situations that have been experienced by disabled people I know that illustrate the possible impact of the new legislation under consideration here and the points I'd like to raise about it. Finally, I have a few recommendations I would like to put forward.

First of all, my background. Although I am a professional, my career has only a slight bearing on the issue at hand today in that I've worked in the field of special education for a fair chunk of time. I'm not an expert in the field of advocacy nor a person who brings strong expertise and legal analysis with me. My expertise is in friendship; friendship with one disabled person in particular, as you will see, and to a lesser extent with a number of other disabled people, most of whom are physically disabled and non-speaking. In the presentation that follows mine, you'll see me in the context of that friendship.

I'd like to go through some points that I have picked out of the proposed legislation. I did buy myself a copy of Bill 19. I went to the government bookstore and I paid my \$15 for it, thinking I should be well versed in its contents before I came here to speak to you. That idea faded quite quickly. The opening words put me straight, "The Advocacy Act is repealed." I didn't know I should buy a copy of the Advocacy Act so I would know what I had to know to be well prepared. So I'm not as fully informed about what has been repealed. Reading on, I realized I would also have needed a copy of the Consent to Treatment Act and the Substitute Decisions Act to do a thorough job of familiarizing myself with the bill. So I apologize for being less prepared than I would like to have been, but perhaps I can serve as an example to you of what it's like being a member of the public at large, albeit a concerned member, trying to become well informed enough that I can give some support to a disabled person. There's certainly a rather enormous barrier there in my way.

1530

For my presentation I'll rely primarily on the sort of Coles Notes version that's inserted at the beginning of the act and further along in the health care portion, the Health Care Consent Act, appendix A, as well. I'd like to go through a number of the points about which I have questions or concerns individually.

Item 5 states, "The new act removes all references to rights advisers and eliminates all requirements that rights advice or notices respecting rights advice be provided to a person who is found by a health practitioner to be incapable with respect to a treatment."

Why? What's the point of stripping people of their right to an advocate? Would you accept it for yourself or the people you care about? What's the problem with ensuring that disabled people continue to have access to advocates? I can certainly tell you the problem of denying them access. The case studies I refer to I think illustrate my point, when I go on to that portion of my presentation. But my own experiences in trying to become well enough versed in legislation to become a quasi-advocate in this situation tell me of the very grave implications of this item, of leaving the disabled to rely on such shaky support. It's just not enough.

Clause 23(3)(b) of the Health Care Consent Act seems to me to say that where there's a communication problem, the health care practitioner can determine whether or not effort has been made to communicate with a person and decide that steps that are reasonable have been taken to find a practical means of enabling the communication to take place. What does "practical means of enabling the communication" mean? Why are health care providers not required to ensure that they use the person's means of communicating in their interactions with the disabled? Is it an issue of time, of valuing the time and perceived inconvenience of the professional health care provider above those of the disabled? My case studies address this further. For now, I just want to identify this as a point that needs much clarification and revision.

Item 6 in that first set of Coles Notes—the initial list about informed consent seems to be missing something: no reference to the individual's rights. It lists all the things that have to be present, but there's nothing to refer to their individual rights. Does this reflect what's meant by no longer requiring that the person be informed about his or her rights? At the same time it does indicate there—or somewhere in the document I'm pretty sure I read—that the person being considered should be informed to the same extent that anyone normally would be. I wonder if all of you would want to know about your rights if you were being judged for your level of incompetence. Would you accept being denied access by someone brought in to treat you?

Item 17 protects the substitute decision-makers from liability for the decisions they make. I would ask that you keep this point in mind when you listen to the case studies and when you listen to Aaron Shelbourne when he makes his presentation. No legal liability for their decisions? Again, would you want to absolve those charged with administering to your needs from any liability for the decisions or actions on your behalf?

Item 24 states that there's no longer the need to ensure that someone determining capacity have expertise in the field of determining capacity. Thus, for example, decisions involving people with alternative means of communication would not require the board-appointed person making the judgement to be knowledgeable about the individual's method of communicating. How could that person know if reasonable means of communicating had been attempted? Again, you'll hear from someone, through Aaron's presentation, who uses eye gaze very effectively to communicate. Would any of you feel competent to make a decision about how well that person's capacity to communicate had been assessed, about what degree of effort was extended to communicate?

The section on the Substitute Decisions Act, item 3, seems to enable non-relatives to become decision-makers. I hope that I haven't misunderstood this but I'm not sure. Again, the few examples I will put forward indicate just how frightening the implications of this are for the disabled. The situation is even worse when one contemplates professional caregivers and the licence it gives some of them.

Item 7 of the Substitute Decisions Act states "if the attorney has...grounds to believe that the grantor is incapable of personal care." I thought that this document,



when I first worked through it, focused on determining mental incapacity. Suddenly the word “incapable” through the bill takes on even more disturbing implications. Suddenly we’re talking about those who need assistance in their activities of daily living as well. Is the bill truly intended to infer that physical disability is equal to mental incapacity when it comes to decision-making? Does the government truly intend to give that much control to those who administer personal care to the disabled? Please listen carefully to what Aaron has to say and then review this section of the bill.

I’d like to put forward a few case studies now to illustrate the issues I have raised.

The first one involves a man named Chester. Chester would have been here making a presentation if he were alive. He died a few years ago in his late twenties. An intelligent, thoughtful person, he had CP, which resulted in his need of a communication board to interact with others. Actually, he addressed members of the Legislature on at least one occasion during his short life. I got to know him when he participated in a field test on some software that was being developed to enable the non-speaking to use telecommunications. Unfortunately, he encountered pneumonia and subsequently died.

Chester spent much of his last two months in hospital suffering from that pneumonia. When I visited him I found out that the staff did not use his communication board, which lay on his bed. They also did not develop other means of communicating with him, even though he was an extremely capable communicator. They did not seem aware of the pain he was in. When I told them he was in a lot of pain, they immediately brought more pain-killer medication, but I only visited him as a friend occasionally. There was nobody there almost all the time. Chester was also starving; he attacked the milk shake and the hamburger I brought at his request with the speed and craving of someone who is famished. He needed help eating; he could not feed himself, unfortunately.

Chester needed an advocate. He needed the assistance of an advocacy agency. There are others alive today who still encounter and will encounter this type of experience if the right to an advocate is eliminated. It’s just too vital to take that away from these people.

My friend has been robbed by caretakers in the residence in which he lived. He had his liquor stolen when he was out because the board of directors and the staff there did not deem it appropriate for him to have a lock on his door to protect his belongings when he went out. He had pieces of clothing stolen too, and this was by the staff, the caregivers who were going to be able to make decisions.

He talked to the person in charge of the residence on more than one occasion. Nothing happened. Advocates who learned of his problem assisted him in going to the police. Staff at the same residence made the rules, one of which was no eating other than in the kitchen. This was these disabled people’s home. Residents wanted to be able to snack in front of their TVs in their own rooms or in the common living room. Does that sound like your home?

I’ll give you an interesting observation about the residence. It was noticed that in the one common living room they had, the furniture was almost like new after

seven or eight years of the residence being in operation, save one chair, an easy chair which was used for watching television. It wasn’t occupied by any of the residents because they were all in wheelchairs, but it had been replaced four times. This is the level of care that you’re talking about and the people you will entrust with the decision-making if the bill isn’t changed.

Residents at a home for the disabled were voicing concerns about abuse by staff. This is not made up, I can assure you: being left in a Hoyer lift unattended for prolonged periods of time—I assume you know what a Hoyer lift is—and being yelled at by staff, and much worse. Efforts to talk to the director and to the board of directors by the residents themselves were to absolutely no avail. Nothing changed.

#### 1540

Finally, their concerns reached the office of an advocacy agency. A meeting between the residents and members of the board resulted eventually in a review of practices at the residence. Staff and board members dismissed the statements about abuse prior to the review. I would say they were hardly in a position to make what would seem to be a legal decision about whether or not there was abuse, but they determined that there wasn’t and didn’t want to pursue it.

They were supported, though, in their assertions by somebody from one of the ministries. I will not get into that, but there was a government employee who single-handedly arrived at a meeting with terms and conditions for a review process, the name of a person they should select and the suggestion that the review he had designed didn’t need to include a written report, that a verbal one would suffice.

It was the advocacy agency’s involvement that ensured that an impartial reviewer was chosen, that the terms of reference were revised and that a written report was provided. They also served as a watchdog that minimized the backlash to which the residents were being subjected.

The written report from that review, by the way, still rests with the board. They’re not happy with its contents and they have not released it, to my knowledge, to date. The concerns of the residents have been given substance, and for our purposes here make it clear how very dangerous it would be to give caretakers any decision-making powers over the residents in that facility. I think it also points to how critical it was for these people to have access to people who are advocates and know the laws and know the disabled people’s rights—and knew how to help them get close to having them attended to.

There’s one further point relevant to the review and to your hearing. One reality uncovered by the reviewer was that most of the residents were individuals without parents or family involvement on a regular basis, nor did they have a circle of friends who could advocate on their behalf. The reviewer was quite surprised but then actually, in reflection, realized that many of the residences that have been reviewed to her knowledge have people in the same boat. They simply can’t be assumed to have a caring, supportive family around them, or friends. They are quite isolated from most other people than the disabled and their caregivers.

Bill 19 in its present form would give the staff there, although they have been found to have some major

problems in dealing with the residents, access to decision-making power over the residents and leaves the residents no course to any advocacy agency. Can you really condone that?

I have four suggestions:

—Be sure the legislation does not lump the disabled, especially those who use alternative means of communication, with the mentally handicapped. Do not deem those incapable of looking after their personal care needs with those who are truly mentally incapable of decision-making. Surely we've progressed beyond that stereotype. Ensure that they have the same opportunities, access and rights that we expect for ourselves and of which they are capable.

—Eliminate the section or sections that include the people who are only incapable of personal care in this legislation—just take them right out—and please ensure that any persons who can gain access to decision-making power over the disabled are themselves proven to be sympathetic to their position and are not in a position of conflict of interest. People who are being employed by the residence and the facility in which they work are hardly in a position, from my observation, to make strong decisions that support the residents. In this climate I can be supportive. They need their jobs.

—Do not remove access to the advocacy agencies, particularly for those who for physical or communication reasons cannot easily obtain information about their rights on their own. Assuming that family and friends such as I can fill that role is placing a very unreasonable burden on our shoulders. We are not knowledgeable about the legislation and should not need to be, just to be a friend or a family member. Would you want that requirement as a term of friendship with someone you care about? Would you feel comfortable with the burden of responsibility you were handed and knew you were unable to measure up to it? I could not live with the consequence of knowing that I had been the source of harm because I was not able to grasp some of the legislation that I should have known about to ensure that Aaron got the proper care that he deserves. I just need to know that I can continue to be an expert in the area of friendship, not advocacy.

—Ensure that where a person has an alternative means of communicating, they are given an opportunity to use that means to interact with those making decisions about them, be they health care workers or anyone else. That would mean someone who signs to interpret for a deaf signing person, or allowing time for the use of a communication board. Do not give decision-makers an out because of what they perceive to be an inconvenience.

In conclusion, I would like to suggest that in Canada we settled the issue of personhood many, many years ago. Now we have a Human Rights Code that protects the disabled from discrimination. Has this legislation been considered in the light of the Human Rights Code, or has it been determined that by blocking access to advocacy agencies, you have in effect overcome the issue of the Human Rights Code? We've done a lot to educate Ontarians about the need to integrate the disabled into the community, many of whom are making tremendous strides to take on more and more responsibility for themselves, and very, very happily so.

I urge you to review the draft of Bill 19 to ensure that it doesn't eliminate the supports they have been given, supports in many cases that go right back to a PC government and its initiatives, and that it doesn't put these people at risk at the hands of those who may lack a basic respect for them as people.

**The Chair:** Thank you, Ms Mori. Our next witness is going to be assisted by Ms Mori in regard to communication. There's 10 minutes left.

**Ms Mori:** It will take us a couple of minutes to get organized.

**The Chair:** Okay. There will be a five-minute recess while we get organized.

*The committee recessed from 1547 to 1554.*

**The Chair:** I believe we are ready to proceed.

**Ms Mori:** We're ready.

**The Chair:** Okay, we're now in session. Aaron Shelbourne, through Naomi Mori—and possibly you might explain to the committee how the means of communication is working, Naomi, for us.

**Ms Mori:** Typical of the use of technology, we had a slight glitch, but Aaron had worked at getting an introduction on his computer. He can use a switch here and a scanning piece of adaptation to WordPerfect to create text, and there's a voice component to it. But we aren't able to get that working. Like I say, my expertise is not in areas other than friendship, but he has it here and he's asked me to start by reading it to you, since we can't give you the voiced-out version.

**Mr Aaron Shelbourne (Interpretation):** Hi. My name is Aaron Shelbourne and I am very happy to be here with you today. Thank you for giving me the time to share some thoughts on what repealing Bill 19 will mean for some of my friends and me.

We all have the right to know what our rights are.

**Ms Mori:** Now, Aaron generally uses his computer as well as his communication board. For those of you who are familiar with Bliss symbols, most of the words, the sections have a little symbol and the word with it as well. In some cases there's just a word. He uses this hand. This is the arm that moves his computer, uses his Bliss board, turns on switches. It's quite a powerful right hand, but an important one in his life. He will give me the sign he wants and I will piece them together and repeat the sentence as he is able to provide it for me. We've prepared the points he wants to make, but I think it's fair that he prepare what he wants to say first. I will be his voice from here on.

1600

**Mr Shelbourne (Interpretation):** I was raped. It was a long time ago. If I'd had an advocate, I could get a person to have helped me then. Some of the attendants I told about it laughed at me. The non-speaking are not mentally handicapped.

I moved into an apartment. The advocates helped me to get the apartment on my own. I feel very very happy to live by myself. I can run my own life now. My parents did not want me to move. I knew I could do it. I am a person and I want to run my own life. I am not mentally handicapped. I am only physically handicapped.

**Ms Mori:** Aaron also brought with him some statements from some people who attend the program he goes to at Seneca College, other people who are disabled and



non-speaking. He asked me to read them to you as the final portion of his submission.

Ann Running sent the following:

"I am living in a group home with 10 other people who are also non-speaking. I am afraid and angry over what might happen if this bill is repealed. My living situation is not good and it is not getting any better, even though we have been fighting for changes. It really gets to me sometimes. I get depressed and angry and I'm thinking about the frustrations I experience on a daily basis, all the time. People don't see the truth. We need to be self-advocates. We need people to listen. We need people to tell us what our rights are. I know now that I have the right to live in a home that is free from abuse, but nothing ever seems to change inside my group home. I need services to help me get these rights met. I worry about what might happen if someone other than my family were to act on my behalf. It is scary."

This one's from Linda Diane McQuillan:

"In 1976, one night after I had moved from Bloorview to independent living, I needed to go to the hospital. I went with my communication board to clarify my speech. I explained what the problem was. They were very patient with me and my board, but they couldn't find out what the problem was. I went in about 1 am and they did all kinds of tests the following day, and around 6 pm they wanted to do surgery. Some doctors didn't want to operate because I didn't want to operate because I didn't have anyone there. My mom lived three hours away from the hospital, so they couldn't wait for her to come and sign the consent form. When I went into the operating room, some doctors were arguing about what if I died. So they proceeded with the surgery. They found my appendix had ruptured, and I'm glad that I am here to share that I made it. But what if this happens after they repeal the bill? Maybe someone would decide that I should just be left to die."

This is from Darlene Gallant, who is also in the program:

"I would not like to lose my independence. I would still like to have the right to voice my opinions on my independence. No one copes with what I have to cope with. Therefore, no one knows my needs better than I do. I have to be able to have a say in my everyday needs and be able to say and control the things in my life. I need to have the right to be heard, to the point that things will change my quality of life for the best. I would go out and live on my own. I am still a person with feelings and needs that are to be respected."

1610

The final one is from Mark Campbell:

"If this act goes through, the right to privacy won't mean a thing at all. The right to choose where you want to live will be up to someone else and independent living will be no more. I have a hardworking mom who has stood by me all my life. Now I have to fight for myself. You can depend on someone helping once in a while, but if others make decisions for me all the time, then I won't have a mind, relying on someone else all the time. That's a drag.

"It's unbelievable how they stress independence when they don't really know what it's about. We have been

misinformed about what independence is all about. These choices we are supposed to make: How are we supposed to make them if we have no supports or education about what our rights are?"

**The Chair:** Thank you. We'll have a round of questions. We have about five minutes for each caucus to either yourself or Mr Shelbourne.

**Mr Clement:** Thank you very much, both of you, for taking the time to come here today and express your personal views and your personal experiences with this very important area of citizen and government involvement. I just wanted to say that right off the top.

What I wanted to say and get your reaction to was to assert that what Mr Shelbourne was talking about, the need for advocates—you had an advocate, Mr Shelbourne, who helped you find an apartment. That's under the existing framework, because the Advocacy Commission didn't have any advocates working for it. They just gave out rights advice from the time they started.

I'm all in favour, and I think all of us are all in favour, of having advocates like that out there in the community: friends, neighbours, advocates connected to various advocacy agencies. That is what we want to encourage and foster in our communities.

If I could just add a personal note, in my riding of Brampton South there is an apartment building with physically handicapped persons, whom I visited with a March of Dimes representative. We had a visitation with three or four persons who had different physical handicaps, one of whom was completely bedridden but had access to a computer and was able to communicate through that computer. When I was there, she was able to communicate her dissatisfaction with a particular aspect of her daily routine to the March of Dimes representative, who was then able to effect some change in her daily routine.

It just struck home to me how it is possible, through the March of Dimes, which is a community-based organization—it does have some interrelationship in terms of funding with the provincial government, but by and large is also doing its own thing and raising its own money as well—how that is possible to be there for persons who genuinely want to live by themselves and have access to those community services.

Am I wrong to characterize things that way? Is that not the way to go to ensure that we do have community-based and independent advocates out there who aren't part of a government machinery but who are doing the job—an excellent job, in my view—none the less. Am I wrong to characterize it that way?

**Ms Mori:** Speaking for myself, I would say that the points I was trying to make were that relying on friends and families, such as me, is really unfair, not only to the disabled, because we're not well enough informed, but also to the individuals on whom you're relying, because you're putting a burden on us that we're not equipped to handle. That's one point I'm making.

The other point is that it is a help to have those advocacy agencies in the community, but I have to be reassured that the bill will insist that these agencies be called upon on these people's behalf. Aaron can't be given the option to make a phone call. That's not realis-



tic. So how do we ensure that somebody is there to make sure he knows about his rights? That's not in the bill, unless I've misread it, and it's their need—you see and you picked up on exactly what I hoped you would, that with advocacy these people are able to effect changes, but they have to be guaranteed that that advocacy is made available to them.

**Mr Clement:** I'm not saying it's perfect, and there are ways to improve things. Goodness knows that we don't live in a perfect society, but what I saw was the March of Dimes advocate doing all the things you're recommending we create a whole new infrastructure to do. It just seems to me that she was already there doing those things in my riding and my community that have to be done, and was doing them, I thought, quite effectively. Certainly, the persons who were the recipients of that advocacy felt confident enough that they could go to her with some changes in their daily lives that they wanted to see and she could effect those changes. I'm still trying to figure out why we need an extra layer, why we need an extra infrastructure to do that.

**Ms Mori:** The March of Dimes is doing a lot and Aaron certainly benefits himself from having March of Dimes around. I have watched them providing excellent support. But I read in your bill that there are situations in which it is not necessary to ensure that these people are available to help make decisions on these people's behalf or make sure they know the rights they have in the decision-making situation. That's the kind of thing that concerns me. I also have watched them make some decisions that are very difficult to take because they have financial constraints, so they can't always meet the needs of the disabled to the extent that I believe staff there would always want to, simply because there isn't the money available. In their role, their advice can sometimes be coloured by that. I understand it, but I don't think it's adequate to use that as an excuse for people who are dependent on them.

Aaron is saying that sometimes, in spite of what you are saying, the people who are paid by these agencies don't always understand what it is they're saying. They don't understand their communications, so even though they're well intentioned, they're not the best people to be their advocate.

1620

**Mrs Caplan:** It's certainly a very important presentation for the committee. The issues in this legislation are very complicated and it's helpful for us to understand the need for training, education and understanding of what rights are, and also I think of the barriers that people in the community have and why O'Sullivan identified the issues as clearly as he did, as well as the other reports that have been done.

I really don't have any questions for you, except that some of the changes in this legislation perhaps do not differentiate specifically enough between those people who are mentally incapable and those who have physical barriers and the need for assistance. There's nothing in this legislation that would support, from what I can see, those who are not incapable mentally but have a barrier that does not allow them to participate and therefore to get the assistance and advice that they need.

**Ms Mori:** That was one of the concerns I had. I found very deep in here that statement that suddenly made the switch into "incapable of looking after their personal care needs" from trying to prove incompetence to make decisions. It startled me. I kept hearing people telling me that this was really going to be hard on people who are physically disabled. At first I wasn't convinced, because I thought they were talking about something so different. It really is frightening to think—

**Mrs Caplan:** You've raised a point we haven't thought about before, frankly, and that's very helpful, because the terminology becomes very important. Just because you are incapable because of a physical limitation doesn't mean that you are incapable in the definition under the Mental Health Act as it deals with capacity. I think we have to find a way of differentiating mental incapacity from physical incapacity. That's very helpful to us, and I hope that the ministry will think about that and perhaps clarify for us in this legislation to ensure that someone who is perfectly mentally capable and able to make decisions for themselves cannot be deemed incapable because of a physical problem. So I want to thank you very much.

**Ms Mori:** May I add to that that there's the issue of the communication disabilities? Because I think there's not just the physical but there's the communication. As I say, these papers were written by people who have communication disabilities. You can see that Aaron understood everything you were saying. He gave you a very clear "yes." He can give you just as clear a "no." There's absolutely nothing to prevent somebody who's working with him asking him "yes" and "no" to determine what he wants. I don't think they should in any way be absolved from being required to do that.

**Mrs Caplan:** Of course, the concern that I've been expressing over and over again with this legislation is that if someone is deemed by this legislation to be incapable, even though it's a communication problem, the provider of service to them doesn't even have to tell them that he's determined that they are incapable to make their own treatment decisions and does not have any responsibility to inform them of their right to appeal. Further than that, if he does those things, nobody can challenge him or sue him after the fact. So while the intent of the legislation certainly, I don't think, is desirous of causing harm—I'm not questioning the motives—I do think you've identified a problem for us of people who, because of their language or physical disability, communication problems, could be in a very serious situation where they're deemed incapable when they are not.

So I would ask for some clarification from the ministry at some point to address that issue to see whether or not there's any safeguard here for individuals who have communication problems, by any test, provided that the assessor or evaluator was trained to understand the language board or the communication tool, would make sure that a person was not incorrectly assessed as being incapacitated for the purposes of this legislation.

**Ms Mori:** One of the intentions we had was to make it very clear to you the level of concern that comes into—you know, what's behind the decision-making that some of these people might put forward. Aaron's parents



said they would not visit him when he moved. They said they would not, they were so convinced he couldn't live alone. Gradually, they've changed their minds because now, after four months, they've seen a difference. But those parents would never have agreed.

**Mrs Caplan:** Again, that's an example of the well-meaning family who obviously love their son and want to see him well but are worried about him taking the risk of independent living and so, while meaning well, are not allowing him to achieve his potential and desire to live on his own as independently as possible. Nobody can fault that family and say they don't want what's in his best interests, but he's perfectly able to make decisions for himself, and I think that's something that we would all want to see accomplished.

**Mr Ron Johnson (Brantford):** On a point of order, Mr Chairman: It's a moot point in that the legislation clearly defines "capacity" and in the definition of capacity it refers not at all to the physical ability of the patient in question. It's purely the ability to understand and that's here.

**Mrs Caplan:** That's the concern and that's—

**The Chair:** It's properly noted.

*Interjection.*

**The Chair:** Well, we'll discuss that in clause-by-clause. Mr Marchese.

**Mr Marchese:** I just wanted to thank you both, Naomi and Aaron, for your presentation, and thank you particularly, Naomi, for the kind of support that you give to individuals. You define yourself as an expert in the area of friendship, and that's something that is valuable and that is wonderful to see. But you've said, in response to another question from one of the other members, that society can't simply rely on people like you to solve many of the problems that people like Aaron have experienced in the past and are experiencing in many institutions, wherever they are.

So as much as some of the government members would say, "Yes, we've got to work more to get more volunteers to do the job out there and we've got to get the agencies, of course, to take the responsibility that they've always had in the past," there are still problems. That's why we created the commission. In spite of the friends who are there, in spite of the well-intentioned people who are there, and family members and so on, in spite of the various advocates who are in the various agencies, there are still many, many problems.

As a result of that, we created the commission, whose purpose was to get to some of these other problems that traditionally we have not been able to solve. So what does this government do? It repeals the Advocacy Act. They get rid of the commission, the rights advocates, because they say: "These people are simply too intrusive in their roles. We should just leave it to the family members, who are well intentioned and very good and loving, and in that way we will solve things." Well, if that were the case, we would not have needed to have developed the Advocacy Commission that we created. It's a problem.

I'm worried about what they're proposing, because I'm not sure what they're proposing, after the repeal of this act. I think this government and these members have an

obligation, before they repeal it, as I know they will, to present something to this committee as to what they have to propose in its stead. So I am looking forward to some of these members presenting something to this committee before it's been repealed, because I think we have a responsibility on this side and people like Aaron have a responsibility to hear what else they propose to help out.

**Mrs Boyd:** I wanted to thank you very much for coming too, because I think one of the things that we need to be very well aware of is that capacity assessors, if they cannot understand the person whom they are assessing, may think that person is not capable of making decisions, and we've seen that. Those of us who have worked with people with all sorts of developmental and communication disabilities know that very often that this has been the decision, that they are incapable of making personal decisions, and people have acted as guardians for them. The public trustee and guardian office will tell you that very often they find that people for whom they have been appointed as guardians don't need guardians for decision-making, but somebody decided they did. They didn't know their rights. They didn't have a right of appeal.

So while there are many fine agencies like the March of Dimes and Cheshire and Community Living and all sorts of groups that do a lot of good advocacy work out there in the community, it is not specifically—and very often they do not have the authority to act as the decision-maker against parents. This has been a long-standing fight in terms of the deinstitutionalization of people from institutions for the developmentally challenged. It is one of the issues that keeps carrying on. It's one of the reasons why the ability of a person to have the capacity to name a decision-maker who is not necessarily a parent may be a very important thing. That's the point that Aaron has brought forward, that being capable and being able to communicate about being capable may be two different things. That's what we have to keep in mind as we listen to some of our other people who come before us. Thank you.

**The Chair:** Naomi and Aaron, thank you for giving us a new perspective on the act and what we are considering here today.

1630

#### INFORMATION AND PRIVACY COMMISSIONER OF ONTARIO

**The Chair:** Our next presentation is Mr Tom Wright, Information and Privacy Commissioner. Welcome.

**Mr Tilson:** Mr Chair, the Attorney General has asked me to provide to the committee a copy of a letter which hopefully would assist the committee at the time Mr Wright is making his presentation, a letter to the Attorney General dated January 29. I have made sufficient copies of that for all members of the committee if the committee would like to receive that letter. I think it would be useful in the committee's deliberations.

**The Chair:** I'm sure. Our apologies for inviting you just yesterday. That was done at the request of Mrs Caplan and with unanimous agreement because we were looking forward to hearing from you. It may not have



been a great length of time to make a formal presentation, but we have at least a half an hour, and I'm sure there will be many questions during that period also.

**Mr Tom Wright:** That's fine. Perhaps what I'll do, just by way of opening comments, is to say I'm quite happy to be here. It was short notice. However, we had been involved with Bill 19 before we were called by the committee, so this did not come as, shall I say, a total surprise to us. With me this afternoon to my left is Ann Cavoukian. Ann is the assistant commissioner of privacy. To my right is Ken Anderson. Ken is director of legal services in my office. Both of them are available, as well as myself, to answer any questions you may have and, probably just as importantly from my perspective, to assist me in addressing any questions you may have.

I thought that rather than even attempt to do any kind of a formal presentation, and in light of the fact that you now have a copy of the letter that my office sent to the Attorney General, perhaps I would just take a couple of minutes by way of a quick preliminary and let you know what has happened since that letter was sent. Quite a bit has happened, actually, since the letter was sent. Most importantly, there was a meeting last night involving myself, two members from my office and representatives from the Ministry of the Attorney General. We went through the concerns that are outlined in the letter of January 29. I'm going to just run through those concerns and where matters stand in terms of those discussions.

Beginning on page 1, specifically, we raise a concern around the public register which is contained and referred to in subsection 60(1) of Bill 19, clause (c.3). The concern we raise is one that relates to the way the Substitute Decisions Act, which is where my remarks are directed this afternoon, is worded now and where it's going under Bill 19. In fact, what is happening is that what is set out in statute in the present act will now be addressed in a regulation.

We've expressed concerns, as some of you I'm sure have heard before, about that kind of a shift. We have come up in previous circumstances with ways of addressing that kind of scenario when it is a regulation that's being looked at and we've discussed that same sort of approach with respect to Bill 19. I have to say that the meeting that took place last night was very positive. In fact, the representatives from the ministry showed a very real appreciation for the concerns we had raised as well as a willingness to have them addressed. I certainly appreciate that response to the letter we have sent.

I also think it's fair to say that in some ways the regulation holds the potential for better privacy protection than would have existed under the previous legislation. What happens with a public register is that none of the privacy rules that exist in the Freedom of Information and Protection of Privacy Act apply to a public register. The regulation, however, makes reference to the possibility of having rules which would govern the disclosure of information that was contained on that public register. I think that, again, holds the very real potential for an improvement of the status quo as we see it in the present Substitute Decisions Act.

We spoke last night about the possibility of an undertaking from the Attorney General which was similar to

what took place with respect to some of the health provisions in Bill 26. I understand that there is the very real possibility that this undertaking would be forthcoming. What that undertaking would do would be to commit the Ministry of the Attorney General to bring to the attention of my office any regulations that would be enacted pursuant to this regulation-making power before they had been introduced. As I commented with respect to the health legislation, I think that in itself is a positive step as far as regulation is concerned and I have to say that it does go towards addressing the concerns in moving from statute to pure regulation. I think it's an important development. I'm not sure if this is going to be a trend that we're going to be seeing down the road, but I see it as something that's necessary when we move into this perhaps somewhat new way of enacting laws.

The other area that we touched on—and I appreciate the fact that this may be overly technical in terms of something that a privacy commissioner would say—relates to subsection 60(3) and a provision which says “for the purpose of sections 38 and 39 of the Freedom of Information and Protection of Privacy Act, authorizing an institution as defined in that act to collect personal information, directly or indirectly, for a purpose relating to this act.”

We raise this concern because it just simply talks about any institution that could come under the Freedom of Information and Protection of Privacy Act, of which there are hundreds. The question we raised was, “Could you be more specific in terms of the kinds of institutions that you'd be thinking of?” The response was, “Yes, we think we can.” In fact, some suggestions were made as to what those institutions would be. So there will be an opportunity for further discussions to try to identify a little more carefully and to narrow, which I think is a very important step, the potential for any institution collecting personal information directly or indirectly.

The final concern, and it's one I know other presenters have directed your attention to, relates to subsection 60(3), clauses (e.4) and (e.5). To describe it, of the concerns that we've raised these two provisions would be the most significant. The reason that they're the most significant, in our view, is that they—and (e.4) in particular—identify individuals, groups that would have access to personal information, that could have personal information disclosed to them, that are not covered by the Freedom of Information and Protection of Privacy Act. There is another grouping, the public guardian and trustee, of course, that is covered by the act, so we understand that.

#### 1640

We discussed this in some detail last night, and one of the things that came out of our discussions, and I think it has some real potential for addressing those concerns—there are really two parts to it. One is to link (e.4) and (e.5) so that you cannot do (e.4) until you've done (e.5). As for how you would actually mechanically do that, we haven't got to that point in any discussions, and I don't know what discussions might have taken place. But it was felt that—and this is my understanding from talking with people in the ministry—it was the intention that this would happen. By actually making it happen and address-



ing it in language in the legislation, there would be an opportunity to make sure it happened in that way.

That addresses part of the problem. That addresses the part of the problem relating to the use and disclosure of the information that you obtain under (e.4). What about the concern about the types of people who aren't covered by the Freedom of Information and Protection of Privacy Act? Again, I think a way was discussed that has some potential, and that would be by amending (e.4). It would be by adding something in the introductory words which would be along the lines of "subject to the conditions set out in the regulations."

What that would allow to be done in regulation, which would be reviewed by the Information and Privacy Commission, would be to set up some rules around the information that's being disclosed, the retention of the information. It could include some confidentiality provisions around that. It might even possibly include in there some kind of penalty provision. What it does, though, is it firmly puts in place some kind of controls around what people who obtain this information who are not covered by the freedom of information legislation can do with it. I think that in our discussions last night there was an appreciation that this would be a good idea, that it was the intention. In fact, I think we have some positive ways of looking at how that might best be done.

I guess the last comment I'll make: As for how the meeting is progressing, we've agreed, since we met last night and only had an opportunity to go over these matters in—well, it took an hour and a half, actually; the meeting went on for a fair while. But we wanted to go back and think about it some more. I spoke with Jay Chalke this morning, and the intention would be that there would be further discussions taking place at a very early date in the next several days with a view to trying to implement some of the suggestions that I'm making to you. I guess that's where I would leave it, as far as the committee is concerned.

As I say, I think on balance there are ways to address what I feel are the concerns that exist with respect to the regulation and, once again, I go back to this notion of the regulation and the review. I'll leave it at that.

**Mrs Caplan:** First of all, thank you very much for coming on such short notice. The concerns that you raise particularly about the amendments to (e.4) and (e.5) were also identified by a presenter earlier today from the Psychiatric Patient Advocate Office, and I must say that our researchers identified that problem as well, and that was why I called you. You've said that that is a problem and that you're working with the ministry now to come up with some amendments that would fix the problem. Is that a fair categorization of the issue?

**Mr Wright:** It is.

**Mrs Caplan:** I guess my concern is that this bill was tabled on November 15 and from your letter it states very clearly that you'd had no discussion with any of the ministries prior to the tabling of the legislation, even though it contained provisions that were going to seriously or potentially have an impact on the collection of personal information and the disclosure of personal information. Is that correct?

**Mr Wright:** As I recall, the bill was tabled in mid-November, and certainly in advance of that being tabled

there were no discussions. To be absolutely fair on this, the lateness of my writing to the Attorney General is entirely my responsibility. It is not a reflection of anything other than the fact of, in the recent while, a fair volume of work and an inability to get at it as quickly as I would like to. I just want to make sure that that's clear.

**Mrs Caplan:** I know the work that you put into Bill 26 and the concerns you had expressed there, so I know how busy you have been. But, linking the two, given the concerns about potential breaches in confidentiality and access to records and all of that which came up during Bill 26, I would have thought that the ministers involved in this would have said, "Given what we know about Bill 19, maybe we should call and check and see whether you have any advice." I just wanted clarification for the record that, until your letter dated January 29, there had been no communication, as you say, mutual—they didn't call you and you didn't call them. Is that fair?

**Mr Wright:** That's fair. That's correct.

**Mrs Caplan:** Again, a concern I have is that legislation is tabled, goes through second reading and concerns are identified which could have been dealt with in advance if there had been what I would consider a reasonable and appropriate communication or consultation with people with expertise. That's the concern I have.

Given the kerfuffle, I guess is the only word, and the absolute embarrassment of the government on Bill 26, and I'm not asking you to comment on this, I can't understand why none of your ministers would not have picked up the phone and made the call to say, "Would you have a look at this before we get to committee?"

I appreciate your coming. I also appreciate the fact that you're working with them and I expect that there will be substantive amendments. But I do have a question and I share with you the concern and the trend for moving from statute written in law to regulation because that can be done behind closed doors.

**Mr Leadston:** Point of order.

**Mrs Caplan:** My question is, do you think there should be notice when a reg—

**Mr Leadston:** Point of order.

**The Chair:** There's a point of order on the floor.

**Mr Leadston:** Mr Chairman, we do have a letter from Mr Wright which says in the closing paragraph that he was contacted by the administrative assistant to this committee—

**Mr Grandmaitre:** That was after it was tabled.

**Mr Leadston:** —and asked if he wished to appear, and he indicated he did not wish to do so. Am I in error of this?

**Mrs Caplan:** Is that a point of order in the middle of my questions? Is that appropriate, Mr Chairman?

**The Chair:** I don't believe that's a point of order, but the clerk feels that it might reflect on the committee and she'd like to comment on it.

**Clerk of the Committee (Ms Donna Bryce):** We had a request from John Eichmanis of the commission to appear and that's what prompted our call to the commission.

**Mr Grandmaitre:** After it was tabled.

**The Chair:** We'll delete that time from your questions. You've got one minute left.

**Mrs Caplan:** Thank you. This is my question. Regulations are all done behind closed doors. In Bill 26 we brought forward amendments that said: "Post your regulations and give people notice that this is what you're doing before they are enacted. Give us four weeks' notice." With the exception of one case they've refused to do that.

Do you think it's a good idea when it's done by regulation for members of the Legislature and the public to have notice of those regulations? It's nice that you'll have it, but how about the rest of us? Do we get any notification of what's done behind closed doors? Is that in the interests of freedom of information?

**Mr Wright:** Certainly, and this did come up in the discussions on Bill 26, I don't see it as a closed-shop experience. I think, as I expressed at the time, it's extremely important that if my office had concerns, those concerns would be made known more generally. I don't see it as within the ability of the information and privacy commission to decide what should or should not be done on its own as far as these issues are concerned. So I see the benefit certainly of making the public aware of these kinds of concerns in a larger way.

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**Mrs Boyd:** Did you, sir, sort of rely on the issue of regulation to ameliorate a problem because there was a refusal to change the legislation? Would your preference be to change the legislation so that these problems didn't exist?

**Mr Wright:** It's a good question and one that we've talked about a great deal. This was certainly the hope in the letter I sent to the Attorney General. We said, "Here are our comments, but we're making them without knowing some of the reasons behind what's appearing in this legislation. We want to hear, we want to understand, so we can comment in an informed way."

Certainly the discussion last night provided us with a much better understanding of what is going on as far as the Substitute Decisions Act is concerned. I think what it did, in my mind at least, it brought me comfort in saying regulation, with the caveats that we've set, is appropriate. As I mentioned with the one example, it does in fact permit the opportunity for better privacy protection than actually exists now.

I want to say to the committee that this whole notion of finding the appropriate balance is a very, very difficult job. I don't want to come before the committee and I don't want to come before and deal with government ministries in a way that isn't positive, and I think, in order to do that, there has to be flexibility. There has to be flexibility on the part of the privacy interests, and I think there has to be flexibility certainly with respect to where the ministry is going on something. I certainly saw very real evidence of what I thought was flexibility, and a very positive thing.

**Mrs Boyd:** The major concern I think we have is that section that would allow a person who has made or has even expressed an intention to make an application for guardianship to have full access to records. That seems to me to leave vulnerable people absolutely open to all sorts of exploitation, because in fact the person may never make that application, and then they have all this infor-

mation, including sensitive mental health information. It seems to me, sir, that no regulation is going to solve that privacy of information problem and that we have a very big issue on that particular area.

We're not so much concerned about the public guardian and trustee or the assessors, because they have professional relationships and there's some regard there. But if some so-and-so down the line in a family, a nephew, decides that he might want to put an application and gets all sorts of property information, it leaves the vulnerable person wide open in terms of the information that person has to which he is not entitled, and because a person has not even been informed that they might be incapable, they have no way of knowing this is going on.

**Mr Wright:** I understand, as you say, in terms of the potential around that particular group, and once again, I also understand the concern around what a regulation can do and cannot do. I think what would be helpful would be to have an opportunity to see what could be done, and we discussed some of this last night. There are ways, for example, of establishing forms which would have warnings etc on them, penalties possibly, as far as misuse. I think you have to look at it in totality as far as what you can actually accomplish, but I understand certainly what you're saying.

**Mr Marchese:** Some quick comments. When we were in government, the opposition constantly said that what they wanted to see were things in the legislation because they couldn't trust regulation. I have no reason to believe that in this regard the Attorney General wouldn't be very concerned about what you have raised and that in the regulation many of those things would be addressed.

Part of the haste that the government is dealing with in presenting so many bills so quickly and not seeking the advice of people in the field is that it creates a great deal of stress and it creates a great deal of paperwork from a number of people, like the Psychiatric Patient Advocate Office. They said: "For the first time in 10 years, we haven't been consulted. Had they consulted us, we would have been able to solve a lot of the things that we are here today to talk about." So as much as you will be consulted in these areas, some of these groups, I suspect, will not be, and that concerns me.

I am not entirely sure about what's going to happen, but I would feel better if this government, based on your discussion with the ministry staff, would bring forth greater clarity around what you're talking about that you seem to have with them before this legislation is passed, so that we have a better sense of what that regulation might say. Unless we see that, we're going to have a problem with that.

**Mr Wright:** And I appreciate that in terms of what the options are. Again, as I see my role before the committee it is to offer you the benefit of our expertise—

**Mr Marchese:** I appreciate that.

**Mr Wright:** —what the options are and where we have been with our discussions, which is what I am trying to do.

**Mr Tilson:** Thank you, Mr Wright, for coming, on such short notice. I'm the parliamentary assistant for the Attorney General and I wasn't present at your meeting last night, but I certainly will say to the members of the



committee that the Attorney General has instructed me to tell you that his ministry has committed not to promulgate a regulation until consulting with your office, specifically on the content of the regulation. The Attorney General has given me instructions to give that undertaking to the committee.

The impression has been given by the members of the opposition at least that, up until last night, there has been no efforts by the Attorney General to contact your office. I would like you to clarify that. Prior to yesterday and prior to last night, had the Ministry of the Attorney General communicated with you to request consultations with respect to these issues?

**Mr Wright:** Following the sending of the letter, I did speak with the Deputy Attorney General, indicating what we would like to see happen by way of a meeting, and last Friday spoke with Mr Chalke for purposes of actually setting up a meeting. That's the extent of what has taken place up until last night.

**Mr Tilson:** Okay. I have one further question and I think Mr Clement has a question, Mr Chairman.

The amendments you propose in your letter of January 29, if the government is prepared to make such amendments, the question I have is whether or not you are prepared to accept regulatory action, depending of course on the content of the regulations.

**Mrs Caplan:** In advance, just give them a blanket carte blanche.

**The Chair:** Excuse me, Mr Tilson has the floor.

**Mr Tilson:** It's been tempting to interrupt you, Elinor, all day long. It really has.

**Mrs Caplan:** I apologize.

**Mr Tilson:** It's really been tempting and I am holding off. I will continue if you provide the same courtesy to me.

The regulations that you've talked about today—you've mentioned several of them—if those amendments are made, and obviously you have talked about the fine balance between that and regulatory power, assuming there is consultation with you, which the minister has indicated that he is prepared to do, would you be content with those types of regulations?

**Mr Wright:** You have indicated, and I think an important caveat to that, that it would depend on the content of the regulation itself and what is covered in it.

**Mr Tilson:** Yes, of course.

**Mr Wright:** Certainly we have accepted, as far as the concern we've raised, that that would be a legitimate way to address them.

**Mr Clement:** Two questions: First, did you also review the Health Care Consent Act as part of your review?

**Mr Wright:** We did not. I'm sorry, that's not correct. We did have a look at it. I think, reflected in the fact that we have not been in touch with anyone with respect to what's in that legislation, I can say that we raised no concerns.

**Mr Clement:** Could I just then get for the record, very quickly, Mr Chairman, based upon your review of the entirety of Bill 19 and based upon your consultations

with the affected ministry, based on your personal judgement, and with the undertakings that that ministry has given you and the minister has given you, would you now say that you are satisfied, from your perspective as a privacy commissioner, with Bill 19?

**Mr Wright:** I think that's a very important last point to make. From my perspective as a privacy commissioner, I may well be satisfied. But again, I think it is important for me to say that I do not purport to speak for the public of Ontario.

**Mr Clement:** Of course not.

**Mr Wright:** I am offering you the comments that I have based on our expertise and I would say, as we see it, the concerns as outlined have been addressed.

**The Chair:** Mrs Johns, did she not have a question?

**Mr Clement:** I think I asked it for her.

**The Chair:** Okay, then I thank you very much for appearing, and your associates.

**Mrs Caplan:** On a point of order, Mr Chair: Before you deal with the last item, could I know who's carrying this bill for the government?

**The Chair:** The question is, who's carrying this bill for the government?

**Mr Tilson:** The Ministry of the Attorney General has carriage of the bill, and I'm the parliamentary assistant.

**Mrs Caplan:** It's traditional around here to have the parliamentary assistant sit up front with staff, and if there's a question that's raised from presenters, to have it answered right then and there.

**The Chair:** We could discuss that tomorrow.

**Mrs Caplan:** I just thought I'd raise it so you could think about it and maybe talk to them.

**The Chair:** I don't know of any traditions in that regard.

**Mrs Caplan:** It is if there's somebody carrying it so it just facilitates it, and it is a legitimate point of order. If a presentation comes, I have no problem with them using the government caucus time to answer a question that a presenter may have. I just wondered if they'd like to consider that so that people might know who has carriage of this and they're here.

**The Chair:** I'm sure they will put that under consideration.

The last item of business: The subcommittee has reported that it met on February 5, 1996, and recommends that a witness appearing on Bill 19, one Laurent DeGuire, be reimbursed for expenses associated with hiring interpreters, hearing-impaired and francophone, necessary for his presentation in Ottawa on February 13, 1996. I would like a mover.

**Mrs Caplan:** Agreed.

**Mr Garry J. Guzzo (Ottawa-Rideau):** Do we put a cap on things like that?

**The Chair:** Not in this case. He's only going to be there for a short period of time.

**Mr Guzzo:** It's a very expensive town, Ottawa.

**The Chair:** Are there any nays? Passed.

We're recessed until 9 o'clock tomorrow.

*The committee adjourned at 1702.*











## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

**Chair / Président:** Martiniuk, Gerry (Cambridge PC)

**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

\*Boyd, Marion (London Centre / -Centre ND)

Chiarelli, Robert (Ottawa West / -Ouest L)

Conway, Sean G. (Renfrew North / -Nord L)

\*Doyle, Ed (Wentworth East / -Est PC)

\*Guzzo, Garry J. (Ottawa-Rideau PC)

Hampton, Howard (Rainy River ND)

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\*Leadston, Gary L. (Kitchener-Wilmot PC)

\*Martiniuk, Gerry (Cambridge PC)

\*Parker, John L. (York East / -Est PC)

\*Ramsay, David (Timiskaming L)

\*Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Oriole) for Mr Conway

Clement, Tony (Brampton South / -Sud) for Mr Klees

Grandmaître, Bernard (Ottawa East / -Est) for Mr Chiarelli

Johns, Helen (Huron) for Mr Hudak

Marchese, Rosario (Fort York) for Mr Hampton

### **Also taking part / Autres participants et participantes:**

Ministry of the Attorney General

Spinks, Trudy, manager, implementation support and counsel, implementation support unit

Ministry of Health

Perun, Halyna, counsel, legal services branch

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service

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# Legislative Assembly of Ontario

First Session, 36th Parliament

# Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

## Official Report of Debates (Hansard)

Wednesday 7 February 1996

## Journal des débats (Hansard)

Mercredi 7 février 1996

### Standing committee on administration of justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

### Comité permanent de l'administration de la justice

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui



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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Wednesday 7 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Mercredi 7 février 1996

The committee met at 0902 in room 151.

ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

ROMAN CATHOLIC ARCHDIOCESE  
OF TORONTO

**The Chair (Mr Gerry Martiniuk):** If I may call this meeting to order, this is the third day of hearings of the administration of justice committee into Bill 19. This morning we have Father Thomas Lynch present, representing the Roman Catholic Archdiocese of Toronto. Father Lynch, you have the floor.

**Rev Thomas Lynch:** Good morning, Mr Chairman, and members of the committee. I'm here today to speak as a representative of the Roman Catholic Archdiocese of Toronto, the spiritual body that's responsible for over one million Catholics in Toronto and area. The archdiocese is closely involved in health care in a wide variety of ways both institutionally through hospitals and centres of care and personally and professionally in the lives of Catholics. As a lecturer in moral theology at the Toronto School of Theology with a specialty in bioethics concentrating on medical decisions about the end of life, I also have a personal interest in the concerns addressed in Bill 19.

This bill is a much-needed corrective to the troika of bills that it's supplanting. It bears the hallmarks of more thoughtful care in its preparation and consultation with a wide variety of professionals in various fields. It is in that spirit that I offer these remarks for the further improvement of the proposed legislation. Though there are several areas to consider, I shall concentrate on three: the concept and rights of the family, the inclusion of nutrition and hydration as treatment and the lack of a conscience clause for health care professionals.

First, the concept and rights of the family: In our day the family is a much-threatened institution. Not only are social forces undermining much of the innate cohesiveness of the family, but there are powerful philosophical currents that seek a new understanding of the individual. These have direct repercussions as to legislation and action. If the family is seen merely as a grouping of individuals who are together by happenstance or for the purposes of convenience but who remain as separate entities, then the notion of duties and obligations being incumbent upon those family members is tenuous at best. The church has always looked at families as the building blocks of a stable society, and we would wish to strengthen those bonds which hold them together.

The rights of the family are prior to the rights of the state, since the larger political body always exists for the good of the smaller. It is the principle of common good that speaks of the proper role of the larger political body, in our case the provincial Legislature, as being to safeguard the accumulated goods of the smaller constitutive bodies, families and individuals. This is vital to keep in mind, for it's not the government that grants these rights but rather individuals and families that are the innate possessors of them. Thus, any legislation must be crafted so that the presumption of rights would rest with the families and individuals who collectively make up our polity.

The concept of radical autonomy that we see as so prevalent in our western thought would say that a person exists as an entirely separate unit that only relates to others as it chooses or is forced to do so. In effect, the person is totally free or she should be. However, this autonomous ethic flies in the face of our lived reality. None of us can exist without others. To be an adult or child, but especially a child, is to be dependent to some degree. Indeed to be human is to live in an interdependent complex of mutual arrangements and understandings.

These cannot simply be reduced to what are commonly called marketplace ethics. Instead the bonds of altruism, support and love are the strongest and most lasting of human connections. They transform us and define us. I am child, sibling, father, mother, grandparent and so on. Nothing legislated or in a merely chosen course can change that. Because a relationship of this order of reality is not amenable to political will, it must therefore be respected for its prior rights.

But society waxes and wanes in its acknowledgement of the duties and worth of familial relationships. We must exercise due vigilance that parental roles are not casually overlooked because of presumption, social indifference or philosophical agendas. In all human society, the protective and nurturing role of parents is primary.

There is an interchange of mutual rights and responsibilities in families with, understandably, the greater burden falling upon parents. Parents are considered as having the best interests of their children at heart, unless lamentable circumstances might prove otherwise. The decisions of parents therefore should not be casually usurped by the state in any manner.

All children are in need of care and protection due to a perceived inability to properly engage the world, and chronological age is generally, though not exclusively, seen as a barometer of this ability. Societies set somewhat arbitrary standards to serve as benchmarks for social approval of increasingly independent control being granted to children until in law and in socially approved custom they are deemed fully responsible. But parents are to make life choices for children until this time. The judgement as to what is best for the child should not therefore be left to a professional, health or otherwise, unless there is proof that the parents cannot make such a decision. It is their judgement which is central to how much a child may understand and to what degree a child should acquiesce in any treatment.

It is essential therefore that this act before us take these social realities into account in regard to who is to make judgements as to the ability and capacity of children to consent to any forms of treatment. Bill 19 must specifically state that age is to be taken into consideration as to capacity to give informed consent to medical procedures and consultations. Subsection 3(2) of the proposed act is an open-ended presumption of capacity on the part of health care practitioners without taking into account age.

As well, parents must have rights of notification as to what treatment measures are to be proposed for their dependent children. As you know, under Ontario law those are children under 16 who are unmarried. They must have these rights so as to properly exercise the rights and obligations to which they are entitled. Bill 19 needs to specifically set the age at 16 years of age below which a young person would have to have the consent of a parent or guardian to consent to medical treatment.

Second, artificial nutrition and hydration: The legislation under discussion would seem to have very little to say about the contentious and rather poorly understood issue of the provision of artificially supplied nutrition and hydration. However, subsection 2(1) when defining a personal assistance plan refers to personal assistance services to be provided to residents. Those services would include nutrition. Further, subsection 2(3) of the same section specifically speaks of treatments or courses of treatments that may be withheld or withdrawn. Nutrition and its necessary corollary, hydration, would seem to be included here.

#### 0910

There is a fundamental problem with defining nutrition and hydration as treatment. Treatment is dependent upon the agreement of the patient, or her substitute decision-makers, and upon some anticipated benefit for the patient. Care, on the other hand, is a continuing function and must always be provided even if treatment is discontinued. The object and the goal of treatment is to cure. One may subject one's patient to unpleasant, painful or

even in themselves life-threatening procedures provided that cure is the intended result. But with care the situation is radically different. Where cure is not possible, the priority becomes comfort, alleviation of symptoms and the production of a contented patient with a comfortable and relatively pain-free life.

Nutrition and hydration, food and water, do not alleviate conditions. Rather they are necessities of life, and so much so that their provision is symbolic of the very essence of altruism and charity. They should no more be withdrawn than should services of hygiene, palliative measures, human contact and spiritual sustenance. It is only in the final stages of the dying process that withdrawal of food and water should be allowed. In such extremity the patient is no longer able to assimilate these various elements and an undue burden would result.

Food and water are essential for all persons. It does not treat a particular condition and, overwhelmingly, its delivery system does not pose a great burden. Since food is never ambient—that means you just don't happen to find it around—but must be artificially manipulated in its preparation and its eating, it is the height of hubris to attempt to differentiate between the types of delivery systems. After all, we don't send people out to graze. Without feeding or water there is only one inevitable result—death. Instead of allowing nature to take its course, we would thereby introduce another cause of that death and thereby responsibility for it.

In chronic care centres or hospitals with shortened staff, with less time for individual feeding, there has been a tendency to resort to tube feedings to assist nurses and not only patients. As well, in hospitals increasingly doctors are facing families with the choice of not feeding a loved dependant and presenting this as a treatment option while talking of a lowered quality of life.

It is here that Bill 19 gets into incredibly shaky grounds. Clause 57(2)(c) speaks of quality of life, and though it's a term well loved in ethical circles—and believe me, I know—it's one that is notoriously hard to define. What is proper quality of life? Quality of life used to be used with regard to the burden and benefit of treatments. Now, however, the ambiguity of the term leads inexorably to debate about the actual worth of the person undergoing the treatment.

We in the church hold to the sanctity of life regardless of disability and the inability of another person to make decisions about the quality of a person's life. One may evaluate the effectiveness and benefit or burden of care, but quality of life is too fraught with baggage to be used. It's a term consistently used in mercy killing debates and one which is like quicksilver in its refusal to be pinned down. In these types of discussions before us now, it is not the means that are the burden but the life itself.

The use of "quality of life" in clause 57(2)(c) is too loose and opens itself to serious abuse. It should therefore be struck so as to avoid the confusion of medical terms with philosophical terms which would open a legislative door to proponents of euthanasia. Such has already happened with cases such as Cruzan and Busalacchi in the United States or Bland in England where euthanasia proponents in ethical circles and on the bench spoke openly of the intended result of obtaining death for



persons of a "poor quality of life," either by dehydration or direct killing.

Thus, in the same regard, definitions of treatment should categorically delete nutrition from their list. "Quality of life" should be stricken as a consideration for treatment plans and personal assistance services in this legislation due to its ambiguity, inappropriateness and potential for abuse.

Third, conscience rights for health care workers: We are all well aware that we live in a society that does not have a shared vision of what is ethically proper and reasonable. In our post-modern world, individuals routinely do not share a common moral vocabulary with which to discuss issues such as we are doing today, and this is a problem that I'm sure in all these weeks has been brought before you consistently. We merely have to look around to see that, especially in areas of life and medical care, people come from a wealth of different backgrounds and honestly disagree about fundamentals such as life and death, rights and responsibilities.

Such moral language disarray means that legislators such as yourselves must be definite in building into legislation such as this an overt protection for the ethical principles of health care practitioners. We can no longer routinely assume shared visions of what it means to be human, what a full and worthwhile life is, the worth of treatments and attitudes towards life and death and many other issues.

In our pluralistic society it is not only patients that have rights of conscience and choice of action that must be respected but also the health care practitioner. As a society, we must not fall into the trap that says that the seemingly pragmatic course is the best or properly ethical one. Too many of us today can leave these arenas where such decisions are made once we've debated them, but practitioners must carry out directives and are intimately involved in the lives and deaths of their patients. They cannot cavalierly remove themselves from responsibility in these decisions, nor would we wish them to do so.

Because of this, a health care practitioner must be able to have her principles and ethical standards protected in law. If not, they will be ridden roughshod over. Practitioners who wish to withdraw from a case or contest treatment or non-treatment decisions must be able to do so in formally approved and open ways, without suffering the consequences in professional dismissal, reproof or the insidiously effective discrimination on the job. Such subtle discrimination can be devastatingly effective at derailing careers.

Nurses particularly, but not exclusively, have validly complained that they are compelled to participate in treatment decisions with which they strongly disagree and which run contrary to honestly held moral principles. It is usually their duty to carry out such decisions and consequently their rights must be overtly delineated.

Health care is still trying to articulate the rights of conscience, and in a rapidly changing system that is under serious pressure. We must build in the overt legal right for individuals to act according to ethical principles without sanction. We need to promote moral values in our health care workers as our caregivers. Therefore, Bill 19 should have a section with clear and definite wording

outlining the conscience rights of health care practitioners in regard to treatment decisions so as to allow for the constitutional rights of such workers to be protected and the decisions of conscience to be respected.

In conclusion, legislation such as Bill 19 will obviously have far-reaching repercussions; therefore, let us carefully evaluate it. Having outlined these points, I thank you for this opportunity to present them to you and to answer any questions that might arise from them.

**Mrs Marion Boyd (London Centre):** Thank you very much for your presentation. I'm very interested in the section you're talking about, the nutrition and hydration area, because that is an area of great disturbance. I too know of many cases where the withdrawal of food and water is proposed to families.

**Father Lynch:** When they are not really capable of making decisions, in many cases.

**Mrs Boyd:** Exactly, and do not have instructions necessarily from their loved one about what they would want at that point. I assume what you're saying is that if we were to be providing real palliative care measures—easing pain and ensuring that people were moved enough to make sure the body sores didn't happen—if supportive care for both the patient and the family were present at all times, the withdrawal of nutrition would not occur until it was very clear that the body wasn't assimilating food and water. Is that your suggestion?

**Father Lynch:** That would be a suggestion. It's a good idea to try to promote the extension of palliative care services in hospices throughout our province. In my own experience within hospitals I have seen that this is definitely the way to go to be able to foster a proper sense of care for both the caregiver and the receivers. However, often the decisions made about nutrition-hydration can begin even in ICU when patients are on the floors, especially for those who are elderly and facing, usually, strokes and mental debilitation. We have to include the basic concept that there would be a presumption in favour of at least beginning nutrition and hydration, however it's supplied.

Normally, these questions don't arise in hospices or good palliative care units because they're discussed beforehand and people have a chance to evaluate their possibilities and their choices.

**Mrs Boyd:** Even in home care, having just been through an experience like that, the old-fashioned sort of training many nurses have is that when the person gets to an almost semi-comatose situation, the suggestion becomes more and more pressure on family: "They don't feel like eating. Don't force them to eat," and so on. I have a sense that very often food isn't even offered. The presumption is, "They're having difficulty eating; therefore they don't want to eat," and I don't agree with that. I share your view that it has to be offered. The patient may refuse, but that's a different issue, isn't it?

0920

**Father Lynch:** I can sympathize with what you're saying, because my own father went through that for almost two years. We were lucky in that, having a big family, a number of whom were trained in health care, it meant people had the time and the inclination to work slowly and consistently to keep up his proper levels of

nutrition. However, in most hospitals we can't blame nurses if they don't have a lot of time to coax people to eat or to take a great deal of time in spoonfeeding. This is a regular complaint on the part of the nurses, that they're feeling rushed in feeding these people. It can be a very laborious process, so we have to be extremely careful to recognize that there are times when that process has its own innate worth.

**Mrs Boyd:** What you say about family in terms of the importance of family, I certainly don't disagree with, although I think we might disagree with what the composition of that family might be.

**Father Lynch:** Actually, it's interesting you have "partners" in the act. But let's not get into that.

**Mrs Boyd:** One of the real issues we have in terms of families is that there is such a diversity in the composition of families, and one of the things this bill does is to set up a sort of hierarchy of family if the person doesn't have the power of attorney and has named someone else.

In many situations—the obvious ones we will hear about are the AIDS kinds of situations where families may have said no, they're not interested in that person, until they get sick and then suddenly want to run that show.

**Father Lynch:** I've been in those situations, actually. I was a parish priest for seven years.

**Mrs Boyd:** It's very difficult, isn't it? When we talk about family, we have to be aware of the context of the family in those sorts of situations being a different kind of family than many of us have thought about.

**Father Lynch:** Being in a post-modern world means that people are going to be making all kinds of choices which aren't based on blood. This is why when people are together in terms of various choices or because of various forced circumstances, we have to be able to see that there is going to be, as you say, a hierarchy of people who will be relatively close to them. You see this in palliative care work when people get extremely close, much closer to their palliative care workers, in many cases, than a family from whom they may have been estranged.

I think those kinds of situations can be handled. I don't think you can ever entirely nail it down as to who the person is who is going to be giving the primary permission, shall we say, for treatment. But there's an openness here, an openness far more clearly laid out than in the previous set of bills, frankly, which caused great problems on the ground in hospitals.

**Mr Ron Johnson (Brantford):** Father Lynch, I have a question with respect to some of the comments you are making in here. I guess you're concerned over the term "quality of life." Can you reiterate exactly what the problem is with that? I'm looking at the legislation and seeing what it says and what the intent is. I just want to get a very clear understanding of your concern with respect to that phrase.

**Father Lynch:** In the early 1960s, the term "quality of life" was taken from an entirely religious context because it was first coined by an adviser to Pius XII. In those circumstances, it particularly meant the types of treatments and was applied to the benefits and burdens of treatments

themselves. Starting in the early 1960s and coming to its fore in about the mid-1970s, "quality of life" started to be applied not to the treatment but to the individuals themselves. The problem with that is that it's very difficult to evaluate the quality of another person's life.

Two of my foster sisters are mentally handicapped, and many people would've said they had a very low quality of life because they were not able to attain any of the socially approved roles in society. But having lived with them, I thought they had a very high quality of life, and I find that when I've gotten sick and people may think I have a poor quality of life, I don't think I'm doing too badly.

One can evaluate treatments and the effectiveness of treatments, but it's extremely difficult to imagine that one could evaluate another person's quality of life. Having dealt with people who are dying and seeing them fight to the end, or others who give up almost when the prognosis is first presented to them, it's almost impossible to enter into another person's mindset there.

I think you should be very careful trying to put this into legislation, because we've seen, especially in the United States, that "quality of life" has been used to very quickly withdraw various treatments or various what we would consider terms of care.

**Mr Ron Johnson:** I understand exactly what you're saying and I understand your concern. Of course the intent in the legislation—and maybe we need to look at rewording that. It's that in deciding what the resident's best interests are, the person—the substitute decision-maker—"shall take into consideration," and one of the things to take into consideration is whether the personal assistance services described in the personal assistance plan are likely to improve the quality of the resident's life. I guess what you're saying is that the subjectivity of that phrase could lead to a number of different avenues.

But when you look at the responsibility of the practitioner, it's clear to me—and maybe we need to look at that again—that they wouldn't be doing anything—you talk about euthanasia—that would contravene any federal statutes, and at the same time, everything they would be doing would be in the best interests of the patient, I would hope.

**Father Lynch:** "Best interests" is a very difficult thing to figure out as well, isn't it? You're going to be spending weeks on that. In this regard, the difficulty with quality of life is that things may be presumed, but until they're spelled out, you've got serious problems. I would refer you to Edward Kaiserlink's work on the quality of life and on the whole area of the protection of life in the reworking of our federal laws. Kaiserlink was very clear that we have to be extremely careful with the quality of life because of how it was being used in various constituencies in the United States. It has been brought up again and again, perhaps misinterpreted, but it's been brought up again and again in many court cases, for instance in Arizona, Oklahoma and especially New Jersey, which seems to make a special hobby of using those provisions in some of its laws.

**Mr David Tilson (Dufferin-Peel):** Obviously, the government appreciates and supports your position with



respect to strengthening the family unit, however that is defined: parents looking after children, children looking after parents and so on, and the extension of that to others, whether it be in-laws or others.

The question I have is with respect to volunteer advocacy. Can you see a role for churches or synagogues or temples, assuming they take the appropriate training processes, in the future participating in volunteer advocacy programs?

**Father Lynch:** Effectively, speaking as a Catholic, we see our church as a community gathered of individuals and families, so it would be natural for us to take that kind of role, to speak out for individuals who can't speak for themselves. That's been part and parcel of what we would consider to be the option for the poor. We would see our distinct role as being able to speak out for people, hopefully on a volunteer level.

**Mr Tilson:** But can you see representatives from your church, for example, participating in training programs to qualify as advocates?

**Father Lynch:** Oh, yes. I think we've done it in almost every other area of social action in society.

**Mr Tilson:** Yes, you have.

**Mrs Elinor Caplan (Oriole):** Thank you for a very thoughtful presentation. You raise a number of issues that have plagued governments and societies for quite a long time.

You mention at the beginning the consultation that took place. My question is, were you consulted as part of the development of this legislation?

**Father Lynch:** No, I wasn't, but as I responded to Marion Boyd's question, I think part of the reason was that I've been out of it with familial responsibilities until a few months ago. But speaking to a large number of physicians and consulting with other ethicists, especially in the Toronto area, I feel I've had an input, and indeed we've had some input. Whether input is taken into account is a different matter.

**Mrs Caplan:** I believe it's very important to talk to the people who have either a front-line understanding or experience with the existing legislation and some suggestions for changes to the future. I've been trying to find out from the ministers what kind of consultation, who was consulted.

**Father Lynch:** Yes, as chaplain of the Catholic doctors' guild in Toronto, we represent several hundred doctors. A number of them, especially those in the ethical areas, have been consulted; there have been meetings, I know, from the Ministry of Health with internists and physicians and other professional ethicists as well.

**Mrs Caplan:** That's helpful, because they have not been forthcoming with who all was consulted, so I've been asking that question. I'm pleased to hear that. My concern was that there was inadequate consultation before some of the changes were made. So that's very helpful. I'll continue to ask that question because I think there were a number of organizations who traditionally have been consulted that didn't have a chance prior to the legislation. If we're here to make good changes to a law that many of us thought was flawed, then I think that's an important part of law development.

0930

**Father Lynch:** I could only add, as a corollary to that, that I don't believe there's any great need to rush this kind of legislation through. It's better, like a good stew, eaten after some reflection. I think the more consultation the better in this area, because it's going to affect pretty well each and every one of us.

**Mr David Ramsay (Timiskaming):** A good analogy.

**Mrs Caplan:** My colleague Mr Ramsay says the stew is a good analogy. I'm not sure I agree.

The other questions I have relate to a part of the bill that you did not refer to and it's something I have concern about. Under this new law they've taken away any obligation for rights advice outside of the Mental Health Act and in the provincial psychiatric hospital setting under the auspices of the PPAO, or the Psychiatric Patient Advocate Office. They've also removed any obligation from people who would do an evaluation of capacity, whether they are doctors or anyone else under the Regulated Health Professions Act who would be able to make that kind of a determination before treatment. There's no requirement to notify the individual that they've been found incapable, there's no requirement to let them know that someone else is going to be making the decision for them, and there's no requirement under the law to let them know of their right to make an application to an appeal board. I wondered whether you've had a chance to think about that.

**Father Lynch:** I think we have to be extremely careful for people, and many of them are on the street. I trained as a psychiatric chaplain, so this is sort of close to my heart. We have to be extremely careful that people have a constant access to be able to have their rights either maintained or regained. In this regard, as far as people are capable of receiving that information and being able to act upon that information, it's a moral obligation to be able to give it to them. The process can be worked out, but there has to be some kind of process there for them to be able to maintain effectively that which is central to human dignity.

**Mrs Caplan:** I agree completely with the last statement, and the concern here is it's not black and white.

**Father Lynch:** I can see why it was left out because the problem was in its working it was very difficult to do, especially in emergency situations.

**Mrs Caplan:** I agree, and there is an emergency provision here that I think is appropriate so that in an emergency situation nothing is a barrier to treatment. However, we know that capacity isn't black and white, that there are people who move in and out of the ability to understand and comprehend all the time. It's a question of understanding that this bill is about mostly that grey stew in the middle; perhaps that's the best way to describe it.

I appreciate your comments. The other issues you raise are things that we'll be thinking about as this legislation progresses.

**The Chair:** Thank you, Father Lynch.

**Mrs Caplan:** Is that it? You're right; you're absolutely right.

## COLLEGE OF NURSES OF ONTARIO

**The Chair:** The College of Nurses of Ontario. Good morning. Anyone that will take part in the presentation, I would request that they be identified for the purposes of the Hansard record.

**Ms Anne Coghlan:** Good morning. I'm Anne Coghlan, president of the council of the College of Nurses of Ontario. With me today are Margaret Risk, executive director of the college, and Elisabeth Scarff, director of policy.

The College of Nurses of Ontario is the regulatory body for approximately 150,000 registered nurses and registered practical nurses in Ontario. Our mission is to regulate nursing in the public interest. The college's standards of practice identify client choice, including the right to information necessary to make choices and to consent to or refuse care, as one of the ethical values most relevant to providing nursing care in Ontario. We are pleased, therefore, to have this opportunity to respond to Bill 19, and most of our comments focus on the proposed Health Care Consent Act.

The timing of the introduction of this bill and our presentation today has meant that the council of the College of Nurses has not had an opportunity to consider either the bill or the college's response. Our full written response will be forwarded to the committee following the council meeting at the end of this week.

Our comments today, however, are steered by the principles, values and concerns which the college has articulated throughout the development and implementation of the current consent, substitute decisions and advocacy legislation, both directly and through our participation in the ad hoc coalition, which will be making a separate presentation later in the hearings.

Briefly, our comments today will focus on: our commitment to maintaining the integrity of the right of clients to make informed and voluntary decisions, balanced with our equal commitment to facilitate the right of clients to receive safe, quality health care in a timely and effective manner, and our concern that overly complex and bureaucratic requirements become undue barriers to these rights; the need for a common understanding among health care practitioners about the intent of the legislation; and the need to address the practical difficulties facing practitioners in interpreting and complying with the legislation in the diverse and complex situations which arise in all health care settings.

We commend the efforts which have been made to simplify the provisions to the Consent to Treatment Act. The form and language of the proposed Health Care Consent Act is much easier to understand. As well, many of our previous concerns have been addressed.

We are pleased to see the amendments to provisions which are often causing unnecessary and artificial delays in the provision of treatment, including the changes to the definition of emergency treatment, the simplified provisions around the definition of informed consent and the elimination of the seven-day wait for notice of an appeal of a finding of incapacity to the Consent and Capacity Review Board.

Other features of the Health Care Consent Act which we support include the ability of the Consent and Capac-

ity Review Board to address situations of substitute decision-makers who do not act in the best interests of the incapable person; the explicit clarification that consent to plans of treatment can include refusals and withdrawal of treatment; and the removal of the purely artificial provision that incapacity to make a treatment decision included incapacity to make a decision about admission to a long-term-care facility.

We also support the removal of rights advice as set out in the Consent to Treatment Act. These rights advice provisions are complex and rigid. We believe they compromise safe, effective and timely care of incapable persons.

We want to make it clear, however, that the College of Nurses does not believe there is no need for clients to be advised of their rights. We are committed to the principle that client rights and decisions about treatment and personal services must be respected. This needs to be done, however, without jeopardizing the quality of health care provided to clients.

Being accountable to act as a client advocate is a fundamental principle of nursing and the College of Nurses' standards of practice. Informing clients of their rights, whether under the Consent to Treatment Act or the Health Care Consent Act, is part of this advocacy responsibility. The College of Nurses has always expected and will continue to expect that registered nurses and registered practical nurses will assist the client to understand relevant information and to protect and promote client rights.

In view of the removal of the Consent to Treatment Act rights advice system, the College of Nurses will be issuing practice guidelines reiterating the professional accountability of our members to be client advocates and providing guidance on what this can mean when there has been a determination of incapacity to make treatment or care decisions. The guidelines will include the expectation that an RN or an RPN who makes a determination of incapacity shall inform the client that a substitute decision-maker will be asked to make the treatment, admission or personal care decision on the client's behalf. If there is an indication that the client is uncomfortable with this intent, we shall also expect our member to advise the client of his or her right to appeal.

**0940**

Despite our overall support for the Health Care Consent Act, we do have some recommendations. We would like to comment today on four particular issues relating to this act: obtaining consent to excluded treatments; the terminology of "personal assistance service"; limiting access to the substitute decision-maker hierarchy on the basis of where a personal assistant service is provided, and whether the consent is required for a plan of personal assistance services; and the need for clarification that consent is required for activities of daily living. As well, we intend to comment on an amendment to the Substitute Decisions Act giving the authority to the minister to pass regulations requiring health practitioners to release personal information to an applicant for guardianship. Finally, we have a recommendation relating to government's plans around the implementation of Bill 19.

Turning first to the issue of obtaining consent to excluded treatments, as the act itself indicates, all common-



law requirements for consent continue to apply to acts or treatments which the Health Care Consent Act excludes from the act's definition of "treatment." The college of nurses has consistently emphasized to our members that nurses should not be providing treatment without consent. This applies whether the client is capable or incapable and whether the treatment is included or excluded from the definition in the act.

We are concerned that in the case of an excluded treatment, the practitioner cannot rely on the list of substitute decision-makers if the person is not capable of giving consent. One of the original purposes of the consent legislation was to give practitioners confidence that there was some legal authority allowing them to turn to family members when consent is needed for a treatment of an incapable person. The rights of incapable clients to have their substitute decision-maker consent on their behalf needs to be retained, whether the consent is required under the Health Care Consent Act, under the common law or in accordance with a practitioner's professional standards of practice.

As well, confusion and uncertainty among health practitioners about who can give consent to treatment when the client is not capable of giving consent will continue to be a barrier to timely and effective care. A consistent and clear authority who can give consent to treatment in all circumstances is required.

We recommend that the substitute decision-maker hierarchy be extended to apply to all treatment whether or not it has been excluded from the definition in the act.

The second issue we would like to discuss today is the introduction of the terminology of "personal assistance service." We are unclear why there is a need to introduce new terminology to describe activities of routine daily living when such activities are widely described in health care settings as activities of daily living. Introducing new terminology to replace a commonly understood health care term seems arbitrary and unnecessary. It is likely to contribute to confusion and ambiguity among practitioners and care providers.

We recommend that the Health Care Consent Act reference to "personal assistance service" be replaced with the term "activities of daily living."

Our third topic today concerns part IV of the Health Care Consent Act and the concept of limiting access to the substitute decisions hierarchy to care facilities as these are defined in the act. We support the concept of allowing providers to turn to the substitute decision hierarchy when a person is not capable of giving consent to assistance with an activity of daily living. We have concerns, however, with the limitation to care facilities. There is no consistency in the settings where personal care services are performed. Services related to activities of daily living are provided in all settings, including unregulated retirement homes, community facilities, the client's own home and hospitals.

Limiting access to the substitute decision hierarchy on the basis of the type of facility where a service is provided is inconsistent with the underlying theme of the first stated purpose of the Health Care Consent Act found in clause 1(a), that is, rules on consent to treatment should be applied consistently in all settings. The College

of Nurses has consistently taken the position that consent requirements should not vary on the basis of location.

In addition, part IV only applies to a plan of personal assistance services. If the service is not in a plan, the practitioner is left in the same position as with treatments which are excluded from the act. Unless there is a power of attorney, guardian or representative, the only recourse is the public guardian and trustee. It is our understanding, however, that the public guardian and trustee is extremely reluctant to become involved in personal assistance matters. The practitioner is again caught in a catch-22: provide the service with no consent or leave the client without the benefit of the service. Certainly, if a substitute cannot be found and the client is in discomfort or is at risk of discomfort or harm, then we would expect the service to be provided even without consent, but in the absence of such circumstances, consent is needed.

The College of Nurses recommends that persons providing services related to activities of daily living be able to refer to the substitute hierarchy, regardless of the place where the service is being provided and regardless of whether or not it is a plan for activities of daily living.

Additionally, we propose that in order to provide clarity, the act include a section that if the substitute cannot be readily located, and a client may incur discomfort or future risk without the service, it may be provided without consent.

Our fourth concern is whether the proposed Health Care Consent Act is precluding the common law on consent for activities of daily living. As we noted earlier, subsection 7(2) of the act provides that nothing in the act affects the application of the common law on consent to treatment which is not captured by the definition in the act. The absence of a parallel provision for activities of daily living may infer that the common law is not expected to apply to activities of daily living.

The College of Nurses' expectation that our members respect clients and obtain consent for acts or services performed for a client does not differentiate between whether the act is a treatment or an activity of daily living. In order to avoid ambiguity, we recommend that the act be amended to explicitly provide that it does not affect the application of the common law on consent to activities of daily living.

Our fifth concern relates to a proposed amendment to the Substitute Decisions Act rather than the Health Care Consent Act. Bill 19 provides authority for a regulation that will require a health care practitioner regulated by the Regulated Health Professions Act, among others, to disclose personal information to a person applying to be a guardian if the information is relevant to the application.

The College of Nurses is concerned that this provision needs more explicit limits on when this requirement can be imposed. Maintaining confidentiality about personal information which comes to the attention of one of our members during the course of providing health care is another one of the basic ethical principles of our standards of practice.

In the case of an application for guardianship, there is no certainty that the person may obtain the guardianship or even that the person has not applied for the guardian-



ship in order to obtain the personal information. We recommend that if practitioners are authorized to release personal information to an applicant for guardianship, the Substitute Decisions Act clearly prescribe safeguards to prevent undue release of personal information.

In closing, we would like to comment on the need for the government to consider the implementation of this new legislation. Only nine months have elapsed since the Consent to Treatment Act was proclaimed. We believe that uncertainty is going to result among practitioners and the public about when consent is required, what the nature of the required consent is and who can give it if a person is not capable.

The College of Nurses allocated significant effort and resources to design and deliver education programs for 150,000 members across the province on the Consent to Treatment Act. We collaborated extensively with the members of the ad hoc coalition to ensure that the messages which we all communicated to our members or stakeholders were consistent, and we did this in a time frame that was extremely short. Despite our best efforts, delays and unnecessary confusion occurred in an already strained health delivery system.

Given the short time period between the introduction of two different consent regimes, combined with the stress associated with the budget cuts, hospital mergers and staff layoffs occurring throughout the health care system, it can be expected that ongoing confusion or uncertainty on the part of practitioners and the public regarding the application of the new provisions will occur for some time.

We urge the government to defer proclamation of any new legislation pending discussions with stakeholders to allow time to educate health care practitioners to facilitate a smooth transition and to provide the resources necessary to undertake a province-wide education program on the new legislation for practitioners and the public.

That concludes our comments today. We'd be pleased to respond to any questions you may have.

**The Chair:** We have approximately four minutes for each caucus. Mr Johnson.

0950

**Mr Ron Johnson:** I want to thank you for your thoughts on the matter and your presentation. I'm grappling with a couple of issues here and a lot of it is sort of the disclosure issue that you talked about briefly in your statement. You said here, "The CNO does not believe there is no need for clients to be advised of their rights...We are committed to the principle that client rights and decisions about treatment and personal services must be respected. This needs to be done, however, without jeopardizing the quality of health care provided to clients."

Is that to say that in some situations, obviously not in a blanket situation, it can happen where the advising of these rights could in fact jeopardize the potential health or wellbeing of the patient? Could you explain that briefly?

**Ms Coghlan:** I could give an example, perhaps. If you have a patient who is already confused or agitated, simply using the term "incapable" first of all may well

not be clearly understood, and secondly, may contribute to greater agitation and confusion.

What a nurse might say in place of that is: "Mrs Jones, we need to make some decisions about your care. Your daughter has in the past made those decisions on your behalf. Your daughter's coming in this afternoon and we will have a discussion around future decisions that need to be made with regard to your care." If Mrs Jones indicates that she now wants her son to be making those decisions, then obviously the nurses had an indication that the client is not comfortable with the hierarchy of substitute decider. If Mrs Jones indicates that there is no problem with her daughter coming—the nurse has checked out the client's understanding of the use of the substitute decider but she has not explicitly said, "Mrs Jones, you are not capable of making this decision."

**The Chair:** Mr Parker. We have approximately one minute.

**Mr John L. Parker (York East):** Frankly, my question was on the same point. Let me get right to it. Right now the act is silent on the point that we just discussed. You have indicated how the profession deals with matters of that sort. Would you have any objection to an amendment to the legislation to include language of the sort that you just described?

**Ms Coghlan:** Yes. We feel that it is covered in our professional standards, that it is a professional accountability of every member of the College of Nurses. Including it in the act resorts to micro-regulation and an infringement on the self-regulation of regulated health professions and quite frankly does not guarantee protection of the public. We currently are waiting for regulations that have been with government for a long time. There would be an immediate accountability of our members because it is a professional expectation as opposed to waiting for a regulation.

**Mr Tilson:** The issue of confidentiality that you asked with respect to I think section 60 of the bill—I guess I'd like to just comment. My interpretation of it is—this is the section that authorizes a member of a college to release information—the section doesn't require the release of information; it simply authorizes it. The nurse or member of another college can choose not to release that information.

I think the intent of this section is that there may be situations where there's no one else to provide information, particularly information with respect to applications of determining one's competency or protecting the individual. But it's still at the discretion of the nurse or health care provider not to release it. It simply authorizes or assists the health care provider to provide that information simply to protect the individual. That is my interpretation of what the section means. It's not mandating you to release it; it simply authorizes you to.

**Ms Elisabeth Scarff:** We recognize that but I think the issue is, should it be the practitioner's responsibility to assess the bona fides, and whether this is an appropriate situation in which to release the information, because the practitioner has no knowledge of the circumstances around the application for guardianship.

**Mr Tilson:** The difficulty is that there may be situations where—



**The Chair:** Excuse me, Mr Tilson. I'm sorry. Your time is up. Mr Ramsay.

**Mr Ramsay:** In a second I'll follow up on that and maybe we can continue on that line. I did notice on the first page of your presentation you mentioned that the timing of the introduction of the bill and your presentation today has meant that you couldn't do a full response. I appreciate that may have a lot to do with the timing of your council meetings that you have as a college, but I was wondering if you were consulted while this bill was being drafted.

**Ms Coghlan:** We have had opportunities to provide input into the drafting of the legislation, and as you know, the college is also a participant with the ad hoc coalition.

**Mr Ramsay:** Good. Following up Mr Tilson's line of questioning I wanted to ask you, when you talked about the release of personal information in regard to an application for guardianship—I know the privacy commissioner has also flagged this and is going to be looking more closely into this—could you give us some ideas of the types of safeguards you'd like to see there that you feel your profession would be comfortable with.

**Ms Coghlan:** Our concern is around putting the onus on the professional at all and the impact that has on the health care provider-client relationship, which is based on trust, and confidentiality is a key ethical principle.

**Ms Scarff:** One suggestion, and we haven't gone into detail about this because we didn't think it was our role: For instance, if there is a preliminary review of the application for guardianship and the court has determined that there is a need for information, then there can be authorization from the court indicating that this is a necessary part of the application. But there would have been that judicial review, which could be done in a preliminary manner through a motion, not through a complicated exercise.

**Mrs Caplan:** I appreciate your view on whether or not there's a requirement to ensure that people know their rights. I've expressed this before I'd like you to think about the position: This legislation removes all rights advisors, the kind of outside, autonomous, non-professional—when I say "professional" I'm talking now about those who would be evaluators or assessors of capacity. So there's no one coming in, with the exception of the Psychiatric Patient Advocate Office, where there are rights advisors. No one's coming in to advise the individual.

There is nothing in the Regulated Health Professions Act that would require consistency among the professions which have the ability to either be an evaluator or an assessor. We heard yesterday from the College of Physicians and Surgeons that they would not begin a discipline proceeding if someone had not advised a patient of their rights and also even advised them that they had been deemed incompetent before they began treatment.

This act does not require persons to be notified when they've been found incompetent, nor does it require any advising of the individuals of their right to appeal.

Do you believe it would be valuable to have some consistency among the professions, perhaps under the Regulated Health Professions Act, so that other professional bodies would be obliged to do what you've done as far as setting up the standards and guidelines of

what would be professional misconduct if a person was not informed of his rights? By the way, I see this as a minimal obligation of providers and I'm asking you, do you think it's professional misconduct if a professional does not inform a person that he's been found incompetent and has not told him of his right to appeal to the hearing?

**Ms Coghlan:** It's professional misconduct if there's been a failure to maintain standards, and our standards are as we've indicated in our submission: that there is an obligation to clearly indicate to an individual that a substitute decider will be used to obtain consent and to advise an individual who objects to the use of a substitute decider of his right to appeal.

**Mrs Caplan:** But that's not consistent in all professions, is it?

**Ms Coghlan:** I can only speak for the College of Nurses. What we're indicating is that our standards and the expectation of our members will indicate very clearly the responsibility—there already is that responsibility now; it's just reinforcing it.

**Mrs Caplan:** Do you think there should be consistency? If there's no obligation, if different professions feel differently than you do, don't you think there's an obligation among lawmakers to at least ensure the consistency in the development of those guidelines by the professional colleges?

1000

**Ms Coghlan:** I think that every professional college has an obligation around consent. I don't think that microregulation of this by government is the answer.

**Mrs Caplan:** I'm not proposing microregulation. What I'm proposing is a statement of the obligation. That's not microregulation. All I'm proposing is that the obligation be seen as serious and that through a statement either in this legislation or a companion in the RHPA it just says it's an obligation, and it's up to you as to what your guidelines are and how you do it, as far as the micro-management of it, because I believe in self-governance.

But there are some court cases that say that unless by statute the government has said that this is a requirement, when tested in the courts, the courts have not been able to uphold that decision. There is one court case unrelated to consent, but it's a concern that I have because not all of the colleges treat the—not for informed consent, but the obligation of informing someone when they've been found incapable, informing them of their right to appeal—not all the colleges feel as you do.

**Ms Margaret Risk:** Can I just respond very briefly to Mrs Caplan? I can understand your concern and perhaps this is an issue that the federation needs to look at in terms of consistency. What we're seeing is increasing obligations in other legislation that begin to infringe on self-regulation. Sexual abuse was one—not to debate that particularly—but this is another, and then there will be another and another. Certainly some of our concern is that the principles of self-regulation begin to be eroded and that we can deal with this in professional guidelines.

**Mr Rosario Marchese (Fort York):** I wanted to make some statements and my colleague will have a question. I appreciated the presentation very much and wanted to comment on two aspects of your presentation.



One has to do with what was just talked about by Mrs Caplan with respect to your ideas around the fact that the rights notification in the past may have been too onerous but that you still respect that the individual should be notified and that you provide guidelines for that. I think that's very good. Saying that you are accountable to act as a client advocate as a fundamental principle of nursing, as a standard practice, in my view is a very good thing to do, and being proactive as opposed to waiting for governments to tell you to do something is very, very good.

I find that these guidelines you propose are guidelines that should be generally applied. I disagree with you in terms of the comment you were making earlier. I think we need to have general guidelines that are in regulation, if not in the act, with respect to rights notification. I'm one who believes that people should know what their rights are and they should be notified of those.

The final comment has to do with the timing of proclamation, and I agree with what you say here. I think many governments make the mistake of passing laws, proclaiming them very quickly usually, and give very little time for people to be able to make the adjustment. This government will not be the first to do this. All of us have done this, and as a general rule, this is a problem. We need to be able to give people time to be able to understand what laws have just been passed in order for people to properly apply and respect those laws, so I think what you suggested here is a very useful thing.

**Mrs Boyd:** My question is around your section on personal care and activities of daily living. We just heard the previous speaker talk about the issue of nourishment and hydration. I wonder if you think that fits under treatment or the activities of daily living and how it would all fit into this whole issue of the continuum of care, because I think you made the point that there is no very clear line between what is a nursing function or a health care function and what is an activity of daily living. I think that's a real concern. Could you give me some examples of what you mean by activities of daily living so that we have an idea of whether your recommendation really needs to have some strength in the legislation?

**Ms Coghlan:** Activities of daily living may be bathing, feeding, ambulating, assisting someone to walk, toileting. They also may be things that in another situation would be considered treatment. Someone with an acute urinary tract infection requires catheterization perhaps as a treatment, but someone may also require catheterization as an activity of daily living, something that is a routine.

**Mrs Boyd:** Like a spina bifida situation or something.

**Ms Coghlan:** That's right.

**Mrs Boyd:** So basically you would want to see the whole continuum of support of the individual in a health care situation be considered as a continuum rather than separated out.

**Ms Coghlan:** That's right, and the same obligation to obtain consent applies to both situations.

**The Chair:** Thank you very much for your presentation. I understand that our next person on the agenda is not available at this moment, so we will proceed, with your indulgence, to Edith Hughes.

EDITH HUGHES

**The Chair:** I understand that Edith is blind and will be making her presentation by tape.

**Ms Edith Hughes:** Shall I introduce myself or have you done that?

**The Chair:** Welcome, Edith. My name is Gerry Martiniuk, I'm the Chairman of this committee, and we have allocated one-half hour to your presentation. Will you be available to answer questions?

**Ms Hughes:** Yes.

**The Chair:** Good. You can proceed then.

**Ms Hughes:** Will they turn on the tape, please.

**The Chair:** Yes, they're turning it on for us right now.

**Ms Hughes:** I understand advocacy to be made necessary from a loss of citizenship, and I come at the problem from the other side. Persons become vulnerable when they do not receive medical care which they require and as a result they lose their rights of citizenship.

I remind the committee that no Canadian at the present time has the right to medical care in spite of great need and in spite of numerous available appropriate resources. The college has stated in writing that if there's any tension or discomfort then a doctor has sufficient grounds to refuse to see a patient. In the event that a doctor refuses to see an individual whom he has seen or for whom he has made an appointment and then cancelled, the college will intervene, but if he genuinely does not wish to see that person, the college will not persist and will provide only a referral telephone service. One is therefore sent shopping against one's wishes into a field that can become more and more narrow.

A physician can refuse to see a person for a number of reasons: (1) he doesn't know enough about the presenting problems and he's not willing to troubleshoot; (2) existing illness, disease or disability can be reasonably attributed to prior or present medical care, that is to say, the problem is iatrogenic; (3) the physician fears real or imagined legal proceedings.

In other businesses liability is seen as a fact of doing business, particularly if one has a monopoly. Consider that Ford is expected to know all about and take all responsibility for all of its products. In medicine the refusal to see a patient for reasons of professional liability is not seen as a conflict of interest but as a right of practice.

The medical system in Canada is a discretionary monopoly. It is a monopoly because a physician is given the right to be the only one individual available to assist; discretionary because he has no obligation to do so. The Advocacy Act, to the degree that it addresses a loss of citizenship due to medical negligence or disinterest, can be considered in this case an operating cost of doing health care as we do it in Canada, and thus belongs rightly in the Ministry of Health.

I propose that the committee consider that if we are to repeal Bill 74, we can do so for this group of vulnerable persons only if we either (1) insist on an absolute medical monopoly, that is to say, medicine must be all things to all persons at all times; or (2) insist on a health care system which relieves medicine of its monopolies in all or some areas of clinical practice and research, that is to



say, we make health care competitive at its most fundamental level, at the level of documentation and diagnosis and interpretation of an individual's presenting problems, and any ongoing referral be undertaken by persons qualified in sciences other than medicine, that is to say, we remove the provision for doctors' orders.

#### 1010

I therefore propose that troublesome physician behaviour is not limited to personality, attitudes or interpersonal factors. That is to say, the need for the Advocacy Act will not be diminished if disengaging physicians become more urbane, listen better, are more approachable or more patient.

It should be noted, though, that this present situation would be improved if medicine and its practitioners could admit they did not know, for there is the added problem that medicine tends to employ psychiatric labels and psychiatric actions or deceptive and casual experimentation on those persons who continue to report and seek assistance for presenting problems which the attending physician deems to be false or trivial.

I propose to provide for the committee the example of vision care, where access to care can be limited by virtue of the usual practice of medicine itself. The unwieldy effects of vision losses, which can be complex, complete and sudden, in growing numbers of persons have a particular devastating effect on citizenship if left wilfully unattended by members of the college.

First, however, I would like to say that in today's medical environment, the Advocacy Act, if left to stand, works to the disadvantage of Canadians who are disabled and unable to obtain safe, adequate and timely care. The provisions of escort, access to medical records and rights advice make physicians uncomfortable and further complicate the problem of lack of care for no good reason.

The remedies for physician misconduct are the college and, failing, that the Human Rights Commission or civil malpractice suits. The above provisions of the Advocacy Act dovetail neatly with a move to legal actions of that sort.

The reality of disability is that one wishes to know if a medical person can assist and, if not, who can? One wishes for safe, appropriate and timely medical care in order to get on with one's life. One does not wish to be swallowed up by the system at such an inopportune moment.

Access to medical records, escort, rights advice, in attempting to get something done, shifts the reality of disability from the action of medicine itself to those aspects of medical culture which are highly politicized, legalistic and defensive. With empowerment of the individual comes enforcement, but one does not need a copy of the medical records of a visit to know whether or not something was done.

What one does learn from those records is how much was understood by the physician of what was said by the patient, how the physician portrays the visit, any derogatory comments and how he justifies non-intervention in the face of need, sometimes through the vehicle of those things which should have been done in an ideal world, such as referrals which did not occur and prescriptions

which were not adequate or not completed at all but show up on a medical record.

Legal proceedings or hearings are a cumbersome David and Goliath affair in a legal forum, where an individual who cannot see and has been used to being a citizen does not find satisfaction or purpose in taking a physician who has not allowed you to use a tape recorder in an eye clinic to a Human Rights Commission five years later. If such actions are attempted and should fail, then one is left even further from health care.

I ask the commission therefore to recognize that the present medical system can be corrupt at any point. Anyone can fall out of the system. In that sense, in the search for medical care when it is needed, vulnerability is universal.

I suggest that the committee consider additions to prevent further withdrawal of services and their consequences for those persons who employ this or any other Advocacy Act in order to obtain needed medical care. It's necessary to recognize that we have a rather fragile infrastructure when it comes to accountability and conflict of interest within the medical system and it feels often that patient activism is the main feature. We lack any science of iatrogenics, any science of games theory or management theory in the present health system. Sometimes it feels like the deck is stacked. I just mentioned the college. There is no complainant or respondent at the hearings and there is therefore no cross-examination. There is no dealing at the college with fundamental theoretical issues, which we'll speak about in a minute. Unusual medical practice is not usually thought to be a denial of human rights.

To the person who cannot receive medical care for no good reason, in some ways the present Advocacy Act is a loss of political will, and a continuation of a reconstructed Advocacy Act without provisions to protect those required to intervene in order to make their needs known while they are disabled without medical care is an act of political cowardice.

As Canadians, we inherit a medical insurance plan put in place by the government in lieu of devising a health care system, now not willing to be a third-party payer. The act of advocacy feels like an attempt to absolve the government of the need to devise a health care program. The act feels like a piecemeal solution in an implicit bottom of accountability in a system continuing with top-up resources. Those at the bottom are expected to work for free and those at the top have resource preference. It is striking how physicians, bedecked with rewards, continue to hold a place of independent authority when discussions of the health care system take hold.

I'd like now to turn to the issue of vision care and I'll refer you to the two pieces of paper which we've handed out, the ICD9-CM table listing of blindness and table 1, which lists distance equivalents for dioptre correction as well as other figures which are self-explanatory.

I consider in vision care that the successes of medical care relate directly to the failures or the places at which advocacy might be required on the ground. In particular, I'm speaking of ophthalmology. When I speak of a success in ophthalmology, I speak about glasses, and it's sometimes referred to as a magic bullet par excellence.

There are some pros, there are some advantages, to glasses. They are numbered and they're objective, and you can see from table 1 that the distance equivalents are very specific. They don't change and they're determined by a Snellen chart which was developed in the 1860s and has a tradition behind it which is assumed to be a valid measure of vision. So in a sense, when you put on those glasses, it solves your problem, it goes away and you can see. With glasses, any person can provide treatment, and many people provide treatment. Glasses are readily commercially available, they're easily removed, they're not invasive usually and they're not considered to have any ill effects.

For a third-party payer like the government, glasses give the government a sense that they know what's been done and for the physician it permits him to determine his time as a businessman and as a clinician efficiently. He can determine how long it's going to take to see somebody. He has a very set procedure for glasses. It's a very easy way to compare one visit to the other. It's a very easy way to learn one patient against the other. So as long as he's prescribing many glasses, he becomes very astute at doing that very thing and he becomes a very reliable prescriber.

So what are the problems? There are a number of quite serious cons that I would like to suggest. In a sense, the tail can begin to wag the dog. If you have something that works as well as glasses, what you can do is you can begin to structure your diagnosis around a rather more convenient diagnosis of myopia. You could tend to overlook other signs or, in the extreme case, you could reject signs which don't fit in with a simple prescription. Or if you prescribe a pair of glasses and someone says they're having difficulty with them, you can say to them, "Well, get used to them and it'll be all right."

1020

Most people are familiar that when you go to an ophthalmology clinic, which is usually what is meant by an eye clinic in a hospital, you will get acuity testing rather than a vision assessment in general and, more likely than not, you will be given a prescription for glasses. That prescription is given in a darkened room usually and it's given using an anti-cholinergic at least once in your life, which is usually based on the drug belladonna or atropine, which in fact paralyzes the accommodation of your eye. It's a drug which prevents the transmission of nerve impulse into the muscles around the eye and so the eye is in fact paralyzed for the time in which it is being prescribed.

There are a couple of dangers with such a structured method or such convenience. One is the tendency of clinicians to do just that. So, for example, a neuro-ophthalmologist has recently said, "Look, I can give you a pair of glasses or I can tell you if you have a brain tumour." Now, I'm not sure that's what everybody from outside would think a neuro-ophthalmologist would do and only do, but that's his impression of what he does and he has no need to extend it, even though there is nobody else who does other things in the foreseeable future. So there is a sense here of the patient fitting into what is provided rather than being observed for what is actually wrong.

That can happen even in the case when the vision signs are absolutely pronounced and remarkable, even by the physician's own measure. They won't show up on the medical record and they will generally be ignored, things like multiple images or severe diplopia or going out of focus when you look at a Snellen chart or, for example, being able to read at variable levels or being able to, once the light comes on, see much better than with the light off or in fact being able to see with the light off.

With glasses, you are at one reading or another. You don't shift around. For example, let's take -10: You don't shift from 20/25,000 to 20/200. It's considered impossible for you to have that kind of range.

I think sometimes too during the assessment there is a tendency to determine whether you could do something and not how you did it. For example, if two people were asked to read a particular line on a Snellen chart, that's the criterion. If it takes one person five minutes to read it and there are plenty of difficulties, and another person simply sits down and reads it, it's considered you're reading. In terms of functional vision, that doesn't really reflect what you're going to have to do when you actually have to focus outside, but for the purposes of glasses or whatever, that's all that's needed to be known.

In ophthalmology there is a tendency—because of the highly structured way in which the assessment is done for acuity with Snellen readings and so on, everybody does their own thing from scratch—if you bring your previous records, not to go from there or to deal with further problems, but in fact start again at the beginning and get yet another reading. Sometimes the readings are not secure, but if you have a reading to leave by, it's as though something was done.

There are two other problems I would just like to mention around the use of high-refractive correction, and I'm speaking now from -6 up. You can see that certain things take hold. One thing I'll just mention to start is that once you put on your glasses, you don't think of yourself as being in any way vision-impaired, and no one else does either. So if you have problems adjusting to the lenses or whatever once you have glasses on or, in the case of some people with very high correction who can't wear glasses as easily, contact lenses, it appears as if you have no correction whatsoever.

It's quite startling to look at exactly what the vision equivalents are. If you look at the table, the ICD9-CM, you will see that after 20/1,000—that is the most severe benchmark measure for total vision impairment in relation to acuity, so anything above -6 without their glasses is considered very, very blind, and yet those individuals themselves know they can't see but they would not think of themselves as blind.

You can go through many years and put up with many difficulties with glasses that are unstable or unworkable, or you could have two pairs, for example, that you can alternate between—headaches, you could have swimming when you turn your head, you could have washed-out colours, a lot of different things—and you would think that basically your vision was really normal and then if you aren't able to wear your correctives at some time, you're in for a big surprise.



There's absolutely no recognition there that any adjustment or visual problems have to be dealt with by physicians or have to be dealt with by the individual, but when the crunch comes, if it does come, then it is the individual left without any preparation for that. There's almost no disability or impairment I know of where it would be completely normal apparently and yet be so fundamentally severe.

The other relationship to that is that in the theory of myopia initially it was about increased muscle tension, and this seems valid once you're in very low levels of -1, -2, -3, and it was originally in that area that glasses were prescribed, but as you go higher up there is no sensible equivalent. People generally think of it not in terms of muscle tension but as an operational definition, so that the meaning of myopia has fundamentally changed, depending on whether it's used for high refractive error or low refractive error, but as a patient you are not told any of this information. It's considered not relevant and yet of course it is relevant if at any time you can't use your glasses. You have no history of these sorts of problems or these sorts of difficulties in prescription.

But the most serious problem of all, and the one that is, I think, most of concern to the Advocacy Commission and its actions, would be the consequences of what we could call a theoretical debate, although it's difficult to have a theoretical debate between a patient and ophthalmologist or someone else in vision care. But it comes down to that because the theory in ophthalmology behind the use of glasses is a theory of the eye which is held only by the medical community.

If you find that within that theory you can't be corrected, you find you also can't be seen by anybody in medicine. And there is nobody else out there. There are professional groups called psychophysics and zoologists and other people who know a great deal about vision, but they do not use a model of the eye as primarily a motor unit, a lens. The view of the eye as a motor unit is that the eye's a kind of camera, but there are many problems with that because the eye in fact doesn't have a shutter and no camera will be without one, and the eye in fact has a soft lens and not a hard lens. There are some other difficulties as well.

All the other theoreticians or all the other people with any kind of practice that you might have access to in research or whatever have really no relationship with ophthalmology, other than they sort of know each other's there and they agree to disagree. If you're in the middle, you find yourself unable to get referrals to these other people and it's very difficult to simply approach them cold.

But other people do not see the eye primarily as a motor unit. They see the eye as a photoreceptor, which is to say that the eye is a sensory organ whose primary job is to deal with light. They have behind them some very good research, which is now many years old, that is virtually unreported in medical textbooks or ophthalmology textbooks. So if you were to actually look at vision and see what it was in a physiology textbook or a biochemistry textbook as opposed to looking at vision in, say, Taylor and Best or another book that was described as the physiological basis of medicine, you would find

that the order of presentation of information and what's in there is very different.

#### 1030

But a theory that says the eye is a photo receptor says that light matters, that it isn't just coincidental to the eye and it's not just gratuitous. It says that impact light has a major influence on whether eyes can actually see and whether they make images and so on. This is a modern theory. The most recent Nobel prize was in 1967 by a professor called Dr George Wald, who won the Nobel prize when he established, over about 20 years, that vitamin A made it possible for the human retina to use light.

If you speak to an ophthalmologist about vitamin A, typically you are told either to go see a nutritionist or that really they don't know what tests would determine it or what the conditions for taking a test for vitamin A are. If you tell an ophthalmologist that when you are in certain light levels or bright lights you can actually see extremely good, certainly they will say to you, "Well, that's impossible with your vision to see that." They will say, "That is absurd," and they will write it down as a claim only of some kind. They will laugh and find it a "miracle." They will say quite demeaning or demoralizing terms. These are the points at which advocacy may prove useful, but it's difficult to know just what advocacy would do.

So I am just explaining here the basic sort of different world view that is excluded from medicine at the moment to really not any good purpose, because in science you must use all the literature that's around in most cases, and ophthalmology is very marginal in a sense. It's absolutely central if you need care; that's what you get. But that is not what we know about the eye as a country or as a community that deals with science. So it's out of step in a very fundamental way. If you happen to have vision which falls into that problem, then that is a real problem for you. It's not a problem for ophthalmology, however.

This is something which is not negotiable. Ophthalmologists will not verify. If you say to them, "Come outside and prove me wrong," they will not actually follow you outside and let you do that, because that is just not relevant to vision care as far as they're concerned. Even if they can't figure out what's wrong, well, then they'll let you go, rather than step out and actually write down on a note, "Yes, she could do whatever it is that she claimed she could do once she's in the light."

I'll just mention another blind spot that seems to also be present in ophthalmology, or in vision care in particular, the way it exists today, and that is the idea that glasses don't cause any problems. For example, if you take your glasses off, the view is—well, it will be just the same as if you had them on, but your eyes will be blurry. That is not the case for some people. In fact, when glasses are prescribed for children, sometimes by putting someone who's been unwell in a dark room, using an anticholinergic like atropine, you actually can give them an artificial reading as high as 6 dioptres higher than they would normally have to induce a high myopia.

Now, if you do that you will see—let us take the case of -10. You will produce a non-transient acuity of 20/25000, which is .00078 of normal sight. You will find you have a globe which is a link—the shape of the eye is now spherical instead of round and it's 3 millimetres



in length longer. So you have a tendency to stretch the retina, you can stretch the optic nerve, and you can cause a malalignment of receptors.

In general, when you wear glasses long term, you only use central vision and the periphery of your retina tends to be degenerative in a characteristic pattern. When you put glasses on you usually focus at the plane of the glasses, so you have one focal point, whereas in normal vision we have multiple, infinite spontaneous focusings all over. So if you take somebody who's had these glasses on—now, the physicians know this is the case but they don't tell you—and when you come out of glasses or can't wear them, you get many optical effects which clearly seem to resemble the removal of correction once had under an eye, perhaps what was wrongly prescribed. But you will not find an ophthalmologist who will take on this problem even though your signs to him would be bizarrely unnormal but they're highly structured in terms of the fact you can track them down yourself or with others' assistance. But you will not get assistance in getting usable vision temporarily.

In finishing, let me suggest that the role of advocacy in this case is quite different. The role of advocacy in such fields that are closed, when they're identified to be so closed to options, and if they're closed on the basis, as I've suggested, of a kind of magic bullet which has in fact taken over the field and the way in which the body part or whatever is determined, and if these people have a monopoly, then if you don't have a body part which behaves in a particular way, you won't get treatment.

If you're talking about a very severe disability, if you don't have cooperation from medical people who are supposed to know and are in positions of authority to know, you have a whole realm of social problems which come from that in which advocacy becomes more and more and more involved. If you wait five years for the Human Rights Commission or whatever, what do you do in those five years? There isn't a problem of attrition here. Things do not get better. People go on with their lives and there you are. You're not getting care and there's a good reason for it, and there is no forum in which there can be immediately some relief provided.

So advocacy takes on a new role and it touches upon telling a doctor how to do his job, which is a very difficult role for advocacy and I suggest is a role that has to be at some point considered, particularly when there are other resources out there which can be brought into play except perhaps for the stubbornness of any particular ophthalmologist or any particular clinic.

In terms of consent to treatment, the question arises—

**The Chair:** I'm sorry, Ms Hughes. According to our clock the half-hour is up and unfortunately we cannot hear the remainder of the tape.

**Ms Hughes:** May I make a comment here?

**The Chair:** Yes.

**Ms Hughes:** I believe my tape recorder actually runs at a faster speed and it's more natural to my voice sound. That's why the tape drags and that's why it's actually longer than the allotted time, because it does come in under 30 minutes. That's, I think, the problem here.

**The Chair:** Not according to my—

**Ms Hughes:** But it's the machine it's been put on, and that's a real problem with tapes. I would really appreciate it—it's in almost the second-to-last line. I'd just appreciate it if you'd just finish it.

**The Chair:** It's the committee's wishes.

**Mrs Caplan:** Let her finish the tape.

**The Chair:** Okay.

**Ms Hughes:** Would you mind? I know it's a problem you're not used to and I did want to explain it. It's so complicated, I had to—

**The Chair:** The difficulty is, Mrs Hughes, that we have people waiting—

**Ms Hughes:** Yes, I appreciate that.

**The Chair:** —and we're behind schedule. That's my fault, not yours. Can you continue with the tape, please?

**Ms Hughes:** Do you have consent to treatment if there's no other way for them to access you—or so they say—but by doing it by a way which is extremely dangerous? So some treatments or assessment procedures which are considered completely reversible and innocuous for most people disable severely other people. Now, there's no research on much of this and it comes down to a judgement call: "Let's just get on with it and see what can happen." But the pragmatic view often gets taken by the patient long before the physician sees the need for that.

The Advocacy Commission becomes involved simply because it is the only agency that has the resources, or would have, to survive over the length of time required. It intervenes now, but it also continues to intervene, if it exists, year on year. Organizations like Parkdale Community Legal Services and so forth exist for the court cases or the hearings at that time. They're not there to collect a file together; they're not to follow through on all the difficulties as things unfold.

I have tried to suggest on this tape what I feel are roles for the Advocacy Commission that I don't think have been yet considered. Thank you for your attention.

I'm sorry there isn't time for questions. Thank you very much.

**The Chair:** Thank you, Mrs Hughes, for your thoughtful presentation.

1040

**Mr Tilson:** Mr Chairman, I'd like to make a motion at this time, if I could be allowed to make a motion, which hopefully members of the committee would agree with. It has to do with an inquest that's proceeding at this time before Trevor Gillmore. I think this inquest was mentioned in the proceedings yesterday. I don't think it's appropriate for the committee to debate the facts of that inquest at this time, but as I understand it, the decision of this inquest is going to be announced next week.

I think it would be useful to the committee, once that decision has been granted, that if there's any material that comes out of that, this committee requests the clerk to obtain that information. So my motion essentially states that we ask the clerk to receive that information from the inquest before Coroner Gillmore as soon as their decision has been made, to assist us in our deliberations.

**The Chair:** I don't know whether their has to be a formal motion. Do we have unanimous agreement on it? Thank you. Mrs Johns?



**Mrs Helen Johns (Huron):** Maybe you could call up the people and I could give a point of clarification while they're moving up. I just wanted to do something with the health consent act, if that was all right.

**The Chair:** Yes. We'll be calling Patricia Bregman.

**Ms Patricia Bregman:** I'm not going to be presenting, but the other three people from ARCH will.

**Mrs Johns:** Rights advice under the Mental Health Act is being maintained. It was something we've heard a couple of times over the last day and I just wanted to clarify that. We're making no substantive changes to the Mental Health Act with respect to rights advice. The only change we're making, really, is who will provide the rights advice. So I just wanted to draw that to your attention, and if you have any other questions, you can ask me about them.

**Mrs Caplan:** If I could, Mrs Johns, I think there should be some clarification on that, because the Psychiatric Patient Advocate Office provides that rights advice, but they only provide that now in the psychiatric hospitals. All of the schedule 1 hospitals that provide or have psychiatric programs at the present time have been receiving whatever advice they get from the Advocacy Commission, as far as rights advice.

**Mrs Johns:** That's right.

**Mrs Caplan:** The concern is, following this legislation, by whom and how is that rights advice going to be provided to other psychiatric programs? It hasn't been clarified and it's not in the legislation. I think there would be a lot of comfort—and personally, I think it should be the PPAO, who have had excellent success in the psych hospitals, who should have the mandate expanded to include the psych programs in not only schedule 1, but if there are any other general hospitals. If you would bring forward an amendment to that or clarify that on the record, I think it would be very helpful.

**Mrs Johns:** For the psych facilities, and it would be the government-run psych facilities, we're still suggesting it would be the PPAO. For other facilities, we're suggesting that it would be put through by regs and the rights adviser will be folks designated by the facility through the regs.

**Mrs Caplan:** You see, that's the problem. The problem is there that the rights advice could be the administrator who would select someone who would have a direct conflict, and that's the issue. The issue is, we believe, I think, that the proposal that a hospital administrator in a general hospital could decide who the rights adviser is is inadequate.

**Mrs Johns:** Okay, but regs could put those criteria in that you wanted.

**Mrs Caplan:** That's the problem, is the regs could do it without any input.

**The Chair:** The time for debate is clause-by-clause, and you both put your views on the record. Now to our guests.

#### ADVOCACY RESOURCE CENTRE FOR THE HANDICAPPED

**The Chair:** Could you identify yourselves for the purposes of Hansard.

**Mr David Baker:** Thank you, Mr Chair. My name is David Baker. I'm the executive director of ARCH, which is a legal centre which serves persons with disabilities across the province. On my right is Etta Ginsberg-McEwan, who is a board member of ARCH and has a long background in social work on behalf of seniors. On my left is Patrick Worth, who has also been involved with ARCH for many years and is the past president of People First, which is the national organization of persons who have been labelled developmentally handicapped.

Let me say at the outset that we're going to have a very difficult time with the time constraints and we have decided that we wish to speak for the 30 minutes. If people have questions, then people know, I hope, how to reach us. If not, we'll be pleased to tell you.

You have a fact sheet about ARCH. Let me just say that we are accountable to the disabled community by fact that 54 member organizations provide the membership and the board of ARCH, and you'll have available, I believe, a list of those 54 member organizations. Virtually every disability organization in the province is represented on ARCH.

There is only one area where ARCH has taken a position in its goals and objectives on a particular issue—over all the years of our existence, only one—and that is the issue of advocacy. It is something which from the very outset ARCH has felt strongly about. All our 54 member organizations endorsed the goals, including the goal of advocacy, as a condition of membership in ARCH.

I don't have time to cover many issues, and I'm going to fly because the two speakers on either side of me have far more important things to say, but let me just highlight the brief for you.

You've mentioned one inquest. There is an inquest ongoing. There is no representation at that inquest from persons with disabilities, which is unfortunate. That may or may not be remedied before the end of that inquest.

I would point out to you—it is referred to in the brief; there are many, I note, that are not referred to in the brief—there have been numerous inquests over the years, persons with disabilities dying in institutions in the community, in a number of settings, where there was a recommendation of advocacy legislation, as proposed by Father Sean O'Sullivan, with a legislated mandate, an independent commission. Those recommendations have come out of numerous coroner's inquests, and I would ask you not to be unduly influenced by one inquest where, for reasons not entirely understood by us, disabled people were not notified that this inquest was going ahead.

The brief touches on a number of circumstances. I would simply say that the issue of advocacy has evolved over a long period of time. A large number of people have been involved. Our brief goes all the way back to 1981, a case involving a young man named Justin Clark; the Abella report in 1983; the Fram report; the O'Sullivan report, on and on. There are four, five, six reports that have been conducted over the years, going back to Conservative years, Liberal years and NDP years. This issue is not a partisan issue, it has not been approached on a partisan basis and we would ask you to think about



it in terms of what is important for persons with disabilities and seniors in this province, not as a partisan issue.

The brief refers to a number of principles. We don't have time to review it with you, but I would point out one thing: The primary principle in relation to advocacy—it's come up in discussion and interplay we saw here today about rights advice—is the issue of independence. It is crucial that advocates be independent. If they are not, they will not have credibility with the people on behalf of whom advocacy is to take place.

You should not be surprised that people are dying on the streets and are being approached by police officers and firemen and are saying, "No, I don't want to go with you." If someone who had actually lived on the streets themselves were approaching those people, the response would be different, but there is nothing like that in place in this province. People who are vulnerable are not being approached by people who have been there, who have experienced what that person is experiencing, and that is something which was critical to the Advocacy Act that was passed and has never had the opportunity to demonstrate its effectiveness.

The second point I'd like to make about independence is that it's crucial if they are going to recruit volunteers as advocates. I heard there was discussion yesterday about the possibility of all people in Ontario, as Sean O'Sullivan had said, being advocates.

The process which led to the establishment of the Advocacy Commission involved nominations coming from 400 seniors and disability groups from every corner of the province. The smallest towns had people who were involved in the process of establishing the Advocacy Commission.

That's important for two reasons. I can only emphasize the second, but the first is that that means the commission was intended to be and was in fact representative of the community it was to serve. The second point is this: Less than 5% of those organizations have any staff person whatsoever. If you believe in volunteerism, if you believe in involving people who are not paid in helping those who are in need, then the solution was exactly what was in place in the Advocacy Act. It was to involve those 400 voluntary organizations of people with disabilities and seniors across the province who were prepared to continue to volunteer their time and asked only for the smallest amount of support from an Advocacy Commission. They were not looking for salaries. This was not bureaucratic. Those 400 groups knew they were never going to see money, but they had hoped to have some support, be given some legitimacy, be given some training perhaps in what it was they had to do on behalf of vulnerable people. That is lost as a result of the repeal of this act.

1050

If you look at, as a substitute, something like the proposal put forward by the commission of a non-profit, it may be possible to link in that kind of effort. But the idea that traditional volunteers such as those you see in hospitals offering tea are going to be able to go out in the streets and help people freezing on grates at night or into institutions where abuse may be happening is not realistic. That is not the person you're looking for as a volun-

teer, those are not the people who are going to help; it's going to be the people who have been there.

**Mr Patrick Worth:** I don't know what I can add to that but to tell you a little bit about myself. I was a person who was labelled as developmentally handicapped and I was put in a special-ed class at a very early age. Throughout my life I was put in one part of segregation or another. I served a lot of time in a sheltered workshop in a group home, which many people may not consider as institutional, but I considered it as institutional because of what people thought, my disability. Nobody really thought about what my capabilities were, and there was a reason for that: The people in my life were people who were paid to service me.

Sean O'Sullivan says that a friend is not someone who can be paid, and he's entirely right. A friend is someone who is there only for the reason of being a friend and to get to know the individual and to get to know how we can all be supportive. When I think about that I think about the one goal that perhaps we all have in life: to be able to wake up in the morning and realize that we are loved and that we are cared about and that we have people in our lives who will come around and be there for the sake of being there because we are friends. To me, the most important part about advocacy is the friend.

Sometimes people will need someone who is paid. In fact, when we look at all of our lives we do have someone who is paid, but there's never been a guarantee that there will be someone in our lives who will be there just for being in our lives. My doctor is paid to give me medical attention. I have to see him whether I want to or not, and sometimes I don't want to. But I'd rather think about who really is my friend in life, the person who will stand by me no matter what. This is what very often Sean O'Sullivan talked about in doing the advocacy review for vulnerable adults. He said that we must pay attention to who will be there for the person in their life.

In 1986, I went to work at the Advocacy Resource Centre for the Handicapped as an institutional outreach worker. I was very excited about this job, about connecting with people in institutions and giving people who have been traditionally segregated a chance to maybe connect with some other people in community life. But ARCH hired me for one specific goal. It was based on advocacy, that was their belief at the time and that remains their belief, as many organizations believe which are connected to ARCH. I have to believe that ARCH hired me based on my advocacy skills and my personal belief that all people can be supported in society and that all people can be a friend to someone.

As I came to believe in this in myself over the years of being segregated, this was the reason why I was so excited about doing the institutional outreach project. It connected me to a lot of people who were still traditionally segregated from this service of institution. I didn't have any surprise as to what the residents didn't know about advocacy or about how people can advocate for each other in terms of support and just being there at a very vulnerable time in someone's life.

I think in many ways advocacy is still new to the individual's life and is still something that people wonder about: What exactly is advocacy? I think Sean O'Sullivan



would say advocacy is advocating for a friend, what he called the assured model, *You've Got a Friend*. I sincerely believe in this. This is why he entitled this review *You've Got a Friend*, because he said time and time again that advocacy must mean you have a friend.

As I looked at my past life I didn't have many. I had people who were paid to service me. It doesn't mean that paid people are necessarily bad, but it does mean that I had a lack of friendship. Service does not always mean support. Service means doing things for people. Sometimes service is necessary, but it doesn't necessarily mean support. Service is that I will provide for you; it doesn't necessarily mean that you believe in persons, are helping them to do it themselves, to have a right, are looking at that person as a person who has choices in his life. We are people who traditionally have had rights taken away from us by people who don't believe in us, by people who don't believe that we can make our own decisions, and we should have a right to decide. Sean O'Sullivan believed in that with all of his heart.

I got to know Sean O'Sullivan when I was representing *People First* on the consumer advisory committee, which was part of putting together this *You've Got a Friend*. I came to know him as a sincere man who came out of his paid role to be a friend to people with disabilities as much as he could. He went around the disabled community, connected people with disabilities, asked for their advice and asked for their input to the review. He went into institutions and talked to the residents—not just the staff who were there but talked to the residents—to see what their lives were like. It made a difference in my life that he was willing to do that.

Sean O'Sullivan was a man who had leukaemia and knew that he probably didn't have much time left. Almost all of that time during his last couple of years of life was spent in trying to develop an independent advocacy system in Ontario. He documented how many people were vulnerable in institutions for that reason and for what reason they were vulnerable. Many people are abused in institutions and can't cry out for help because they are isolated, segregated places and we cannot hear them. That comes to having a part in having a voice. How do we have a voice if we can't hear the people who are crying to have a voice?

When I think about that I again think in terms of my life. I didn't have a voice; I was restricted; I was told what to do day in and day out. I never had a chance to voice myself about what I wanted to do in life, what I could do in life and what I could learn. If you're only going to look at the disability of a person, you're only seeing one part of that person. We all have abilities and that's how we should all be recognized.

I'm going to read part of what Sean O'Sullivan said in his closing remarks about the assured advocacy model and why he believed that advocacy must mean *You've Got a Friend*.

"It needs to be enhanced and encouraged. Volunteer advocates provide the possibility for more widespread and locally sensitive advocacy services. The training of such volunteer advocates is consistent with our belief that advocacy is not just a function of government; it is part

of our responsibility to care for one another as family members, friends and concerned citizens.

"Volunteer advocacy will make a positive contribution to the lives of both the vulnerable adult and the advocate, who will experience the satisfaction of learning that we still need one another and that we can still make a difference in the wellbeing of others in our society.

**1100**

"While recognizing the need for a core of equally dedicated, professionally trained and suitably paid advocates, this review has concluded that the heart and soul of advocacy services will depend upon caring volunteers. Sometimes there is frustratingly little that can be done to change or improve the sad circumstances of some of our vulnerable citizens, but volunteer advocacy can advance the possibility of assistance and at the very least provide vulnerable citizens with the hope and satisfaction that they no longer face their circumstances with the additional handicap of loneliness or abandonment.

"Shared advocacy in Ontario, once implemented, will say to those in need, at the very least, 'You've got a friend.' Sometimes that is the biggest and best difference in all our lives. It is the difference we should be willing to make as we learn, with renewed resolve, to stop acting as strangers when confronted by those to whom life has been less than kind.

"If Ontario is to continue to be a caring, compassionate and progressive society, we must replace fear with friendship and inaction with advocacy. Regardless of physical or mental illness and/or impairment, vulnerable persons must have the power to make decisions and exercise their right of choice. People are people whether or not they have identifiable handicaps.

"The advocacy system is designed to foster in a vulnerable individual a sense of dignity as a valuable contributing citizen of Ontario. There is nothing in this report that cannot be achieved if there is the political will to recognize the genuine needs of Ontario's vulnerable citizens. May we now move forward and never turn back."

I can't say it any better than that; in terms of my life Sean O'Sullivan has said it in here. This could have made a difference in my life a long time ago. Now you have a chance to make a difference in the lives of many people with disabilities across Ontario if this is implemented. Thank you.

**Ms Etta Ginsberg-McEwan:** Good morning, and hello to you, Mr Clement. You and I met November 25, 1995: ARCH priority day. You said you learned a lot from me and the rest of the people. I don't think I was such a good teacher, because you're still at square one. And you, Elinor Caplan, I don't think you're aware of how condescending you were yesterday to Aaron when you said to him at the end: "Your parents are trying to do the best for you. They care about you. They're afraid of risks." I know you meant well, but don't talk to us like that.

What I'm going to ask you all to do this morning is to put on your third ear and listen, and to look with your third eye. Your regular eyes and ears filter out, because you can't bear our pain and you think we're too emotional. Put on your third ear now and listen to us.

How did I get to be this way? I've been disabled most

of my life, and any abuse in the books—physical, emotional, psychological, sexual—you name it: all there. When I was 16 I vowed I would become a better social worker than any who had been paid to service me and who ignored me, and I vowed that any human being whose life I touched would never go through what I went through.

I have kept that vow, so that in June 1995, when ARCH called me to be a volunteer advocate for an elderly woman I thought for a moment, "I just left Baycrest; I need a rest," but I remembered that vow, and we're here on earth to care for one another, so I took it on. This is an elderly woman in her eighties, who lived in Vancouver and the Yukon. She sustained a stroke several years ago in Vancouver, and the family put her in a nursing home, without discussing it with her and without her consent.

Back here in Toronto there's a younger family. This elderly woman raised the woman here in Toronto as a daughter. She didn't officially adopt her; let's call it an emotional adoption. This young woman in Toronto would go to Vancouver to see what was going on and how things were going, and she found her in a deplorable state and brought her back to Toronto for a three-week visit. The woman asked to stay here, and so she did, and the family in Vancouver were in a rage. They took over the Vancouver condominium apartment—the woman has a lot of money—took over the condominium and took all her possessions. To this day we don't know where they are, and the public guardian and trustee has not made a single effort to find out.

About two summers ago, the people here in Toronto, with the elderly woman, decided to take a motor trip to Vancouver and the Yukon to see how things are and visit. After that visit, the relatives and friends complained to the equivalent of the Ministry of Community and Social Services here that this elderly woman was being abused.

What did they do? They didn't call the woman here. Like the CIA and like the RCMP and Gangbusters, they got in touch with the equivalent here in Toronto, and the public guardian and trustee, whom you think so highly of, entered that home, without any call, threatened them, took pictures of the house, said they would take a lien on the house if they didn't cooperate. It was an absolute nightmare.

The elderly woman had spent thousands of dollars on legal fees before ARCH entered. The younger family had to hire their own lawyer to protect themselves from the public guardian and trustee. And then I entered the picture.

The woman was not sleeping; she had bouts of severe diarrhoea; 87 years old, never been subjected to this; millions—I'm exaggerating—of assessors. Be very careful about assessors. They don't know how to talk to old people, let alone young people. I'm sure if they asked you what your bank account was or where your stocks and bonds were, you wouldn't know unless you went back to your files. They made awful decisions. I met with her and gave her a voice. I did not tell her what to do. That's not what an advocate does. And then I wrote, which I never knew I had to do before, affidavits. To make a long story short, we won the case. She now has

complete control over her own finances, and they will be put into a trust company.

The rumour around the public guardian and trustee office that has come my attention is, "Are there any more advocates in Toronto like Etta?"

I want to tell you what you're doing to us. First you repeal the employment equity and Marilyn Mushinski says, "We'll give you computers and we'll give you hearing aids and you can compete." What the hell does she know about attitudes? I cannot tell you how difficult it has been to get a job for people with disabilities. That's the first thing. Now there's a big screwup with Wheel-Trans. Now there is this: taking away advocacy. All in seven months. And then there is the welfare screwup with people who have disabilities and old age assistance.

Do you see the continuum? In olden days they put us in volcanoes. Hitler put us in gas chambers. You are a bit more—and when I say "you," I don't mean the collective you around this table. You are putting us in an institution. You call us a special-interest group. We are not a special-interest group. The reason you can't hear us is because you can be us. You can have a stroke. Some of you are eligible for heart attacks. Some of your children will give birth to children with autism or mental impairments. Some of you will be in automobile accidents. Talk to Ian Scott; he'll tell you how his life changed overnight and how people began to talk to him.

**1110**

You said yesterday, Elinor—I don't know you, really, so I should say Mrs Caplan—you said yesterday that every day we go through it. Well, I'm not physically abused any more and nobody messes with me. But I want to tell you something. Every day is abuse: It's a nightmare of attitudes, of architectural barriers. You have absolutely no comprehension of what it's like.

I looked up the word "justice"—because this is the committee on justice, right?—and this is what it says: "To behave with justice ethically, to act in such a way as to show full appreciation of the worth or importance of others." In seven months we have seen our rights go down the drain.

Let me just close with this. I recommend this book. Tony, read it, because you're a good guy and we could be better mentors for you. You don't have a good mentor. This book is called *Pride Against Prejudice*; it's by Jenny Morris. Read it.

To continue to live as best we can, keeping faith with who we know ourselves to be in the face of what society has decided we are, does take courage. But it's a quiet, unspectacular and, above all, unrecognized courage. Real courage has no witness and no rewards.

I want to leave you with this. We should keep in mind, when we are being treated in this way, that these things generate from the murkier depths of humanity and that they are not perpetuated consciously. We need to make the effort to understand that people are far more disabled by their attitudes than we are by our physical and emotional and psychological conditions, once we acknowledge it unreservedly.

I want to thank you for giving me this opportunity, but I want to tell you, it's humiliating. It suddenly came to me last night when I was watching the replays. It is



humiliating. I feel humiliated to have to come before you to plead for my life. Think about that. Think of all the power you have over me. It's disgusting. It's a shame. Remember how you will be written up in the history books.

But I'll tell you what gets me through each day: There is a high power that I have to answer to and that everybody has to answer to. I'm not threatening. There is a just God. Thank you.

**Mr Baker:** Let me just close with one comment. It's this: We haven't addressed the other pieces—

**The Chair:** You are presently two minutes over your allotted time, so make it very short.

**Mr Baker:** It will be very short. ARCH has not addressed the issue of the other pieces of legislation because, in our view, the other pieces of legislation cannot stand without the Advocacy Act. In our view, substitute decision-making, mental incompetency, whatever you want to call it, is the most serious intrusion on civil liberties of a citizen it's possible to have. It removes every single civil right a person has, and to do that with no due process—one doctor's signature, without advocacy, without mechanisms of informing people that their rights have been removed—cannot stand. It's our position that there is a grave mistake being made if the Advocacy Act is repealed. Thank you.

**The Chair:** Thank you very much for your most stimulating presentation.

#### ETHNO-RACIAL PEOPLE WITH DISABILITIES COALITION OF ONTARIO

**The Chair:** Good morning, Ms Haniff. We have one half-hour allotted to your presentation, which includes questions if there is sufficient time. You have our attention.

**Ms Rafia Haniff:** I apologize for not being here at 10 o'clock. That was because of Wheel-Trans; they were very late and that's why I was rescheduled for now.

I would have liked to make this presentation with other members of ERDCO, the Ethno-Racial People with Disabilities Coalition of Ontario, but a lot of them, when asked to come here, tried to book their rides with Wheel-Trans and were not given rides. That's why I am doing this presentation alone.

Thank you for giving me this opportunity to address this very, very important issue regarding the repeal of the Advocacy Act. My name is Rafia Haniff and I'm the chair of ERDCO, the Ethno-Racial People with Disabilities Coalition of Ontario. ERDCO is a provincial cross-disability consumer organization. Our members are made up of people with disabilities from various cultures, various religious backgrounds and various ethno-racial backgrounds. Our members face multiple disadvantages due to their sex, race, disability, age, poverty etc. Our goal at ERDCO is to promote awareness and understanding of the issues we face, and not only understanding of the issues, but also to help find solutions to these issues.

When we talk about advocacy in this province, we should all remember the words of Father Sean O'Sullivan, who said in his report nine years ago, "Ontario needs advocacy." Today, more than ever, this holds true. Now it is even more urgent, and that is because of all the

cutbacks to services that people with disabilities are facing. People with disabilities are faced with poverty, isolation, discrimination, abuse, racism, sexism—the list goes on and on. The issues are even more serious now. We are at a time in society when the most vulnerable are hurt.

Where is our social conscience? Do we ever think that one day it could be us, that we all will have to grow old some day or any one of us could become disabled, as the previous speaker talked about, at any time? With a stroke of the pen, the government repeals the Advocacy Act, the lifeline for many vulnerable people in this province.

I'm distracted by so many people leaving this room who should be listening. I'm getting very distracted and worried.

Do you ever think of the effects of these mere words on paper, what it means to people with disabilities and seniors? You're just going to repeal the Advocacy Act. For one moment, I would like to take us to these people:

Joseph Kendall, who was admitted to the hospital for pneumonia, died. He was overmedicated, neglected, dirty, disoriented after spending months in a private nursing home. He was abused.

Then there was the story of Chandra and her husband, Harry, both of them with disabilities, living in a roach-infested apartment, very dirty. They had very little to eat and they were both ill. They had to sleep in their wheelchairs many nights because an attendant was not available to put them to bed. The attendant who was looking after them stole the little money that they had and this left them in even a more difficult situation. They were afraid to report this incident because of fear the service was not going to be continued.

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There was also the story of Marion, who was tied to a wheelchair by day and to her bed at night in a hospital. She died when she became tangled in her own restraints and strangled on them.

There was the story of Zulie, who was told to shut up and that she was crazy when she reported that she was sexually abused in a chronic care institution. No one listened to her. She spoke very little English and had ALS, Lou Gehrig's disease. She attempted suicide.

These incidents go on and on. Seniors and people with disabilities have been abused. They have suffered trauma and died throughout this province in alarming numbers and disturbing circumstances. The community is furious. We're frustrated and frightened by this action to repeal the Advocacy Act. This act was intended to lessen this human tragedy. The problems that existed before the legislation will now be increased.

There is no mechanism in place to address these issues. While new and different policies will be drafted, more abuse, more isolation, more acts of indignity and death will occur. The community has struggled hard to accomplish what we've accomplished in the Advocacy Act. With your political whim and uncaring fancy, people will be made to suffer. If the government believes that advocacy will exist because they think it will, then our society is in real jeopardy.

People have their individual rights ignored. This act was a good attempt to inform people of their rights and maintain and execute those rights to the wishes of vulner-



able people. Ontarians have been treated with indignity and disrespect because of their age and disability. This act was to ensure that people maintained that dignity and that respect.

The need for advocacy and legislation was recognized and supported by the Conservative government. The repeal of this act is not a sign of progression, but major regression. If the government sees the need to repeal this legislation and dismantle the commission, what are the replacements? What should we have in place instead of the Advocacy Commission? We know that advocacy needs to be established and supported for it to be effective.

Some of the recommendations that ERDCO is suggesting are:

Ensure that legislation is in place to encourage accountability. One of the things that the Advocacy Commission is proposing right now is a structure of the non-profit organization, cross-disability organization. That is one of the structures that we at ERDCO would support.

We feel that government should make advocacy for the people by the people. Let it be from people with disabilities, and it must be a cross-disability approach.

Education and training must be an integral part of advocacy.

Community development must be an important aspect of advocacy, so it can be effective and continuous.

Rights advice must be given by an independent person and it should not—I repeat, it should not—be left to the discretion of the public guardian and trustee. Rights advice should not be left under the Substitute Decisions Act. We feel that this is a conflict of interest.

Vulnerable people must be an influential part of the decision-making process.

Advocacy must encompass all forms—individual, systemic and non-instructed advocacy.

Institutions, caregivers and family must be accountable for their adherence, or failure, to ensure advocacy is demonstrated properly.

Father Sean O'Sullivan ended his report by saying, "There is nothing in this report that cannot be implemented if there is the political will to do so." In that respect, I urge you to exercise this political will.

**The Vice-Chair (Mr Ron Johnson):** Thank you very much for the presentation. We're going to move on to questions. Each caucus will have about six minutes approximately and we'll start with the third party.

**Mr Marchese:** I want to thank you, Ms Haniff, for your presentation. We've seen you before in the employment equity hearings. I always enjoy hearing your views, because I think they're representative of the people you obviously speak for.

One of the things that I have talked about is the fact that this government has done one of the most irresponsible things by repealing the Advocacy Act altogether. I think it's irresponsible because in its place they offer nothing else. But besides that, I think that it overlooks all the work that people like you have done, people like ARCH, as an organization, and all the people involved with ARCH have done to bring about the Advocacy Act. It overlooks it, it dismisses it and it doesn't say it's important. In fact, what it does say of the Advocacy Commission is that it's intrusive, it's bureaucratic and it's costly. That's what it says. It overlooks all of the suffer-

ing that people like Ms Ginsberg-McEwan, just a half-hour before you, spoke about and the suffering that people like Patrick face on a daily basis.

Although we can't fully understand the incredible barriers and suffering that many of you face, we have a duty, an obligation to listen and to understand how we can better protect, represent and make you more independent, as you should be. So I feel very, very saddened by this government because it continues to take away those few rights that people with disabilities have enjoyed. This is yet another way that they are going to be hurting you. So I'm concerned. I'm concerned because I don't think they also fully appreciate what the Advocacy Act was intended to do. I'm not sure that they have read this piece put out by the commission itself. If they did, I would sense that they would get a better understanding of what the commission was going to do.

I'm not quite sure. Do you have any suggestions on how we might be able to reach people who are not disabled, who are not able to get into your shoes, so that they can better understand why the Advocacy Act and the commission and the rights advisers are important? Is there a way you think that we can reach people who obviously have no way of understanding what the problems are?

**Ms Haniff:** That's a very difficult thing to do. A lot of it has to do with attitudinal barriers. That's one of the biggest barriers we face as people with disabilities. It's the attitude that prevents us from gaining what is ours, from getting where we want to get, from getting that independence we need. We can do a lot of public education, we can do a lot of awareness, but people have to look at their inner self and look at their conscience and think that one day we don't know where we're going to be, and look at our family members, because I think we all know someone with a disability, and reflect that one day it could be us.

**Mr Marchese:** Mr Tilson and Mr Clement speak about ways of strengthening advocacy in the community. They talk about how volunteers could take on a greater job of providing advocacy, how the existing agencies are perhaps the ones that should be allowed to continue to do the work they've done. What we have heard from many people, including Mr Baker, who spoke before you, is that there are very few paid staff that do advocacy, very few. In fact, they're getting less money to do what they might have been able to do. Volunteers are not able to provide the advocacy that should be provided, although no one is obviously not permitting them to do it, but it's just not adequate. Mr Baker and Ms Ginsberg-McEwan talked about the inadequacies of that.

Do you have a response to the point about how we make volunteers do the job better for advocacy, how we allow those agencies, the few agencies that are there, that have staff to do advocacy, to continue to do that great work? How do they do that?

**Ms Haniff:** It's very difficult for volunteers to be involved. They do have a role to play, yes, but the resources were not there before the Advocacy Commission. We've seen the abuse. It's happening. We've seen the rights taken away from vulnerable people. Volunteers were there, but these things were still happening. I think



it's very, very important for us to reflect now, at this present time, when we are faced with so many groups going under because of funding and all the cutbacks. We are feeling the effects. We are being hurt by all these cutbacks.

When this government is going to be defining "disability" to limit who gets access to services, that really, really concerns us as people with disabilities, because we are placed in a situation where the services that we need we can't get because someone defines us as not having a disability. So we fall between the cracks here.

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**The Vice-Chair:** Ms Haniff, we're going to turn to the government side now for about five or six minutes of questions.

**Mr Tilson:** Thank you very much for coming and expressing your views on this topic. I'd like to talk about the issue of volunteerism. You mentioned the disease ALS, and I can tell you that several years ago my father succumbed to ALS, and it's a tragic thing to watch someone go from a healthy individual down to having absolutely no control of one's physical capabilities. Absolutely tragic. It's devastating for the individual, it's devastating for the family.

In our particular case, we arranged for powers of attorney. We knew he was approaching the situation. When he was competent, powers of attorney were prepared and the family cared for him. As well, I live in a place called Orangeville, which is just northwest of Toronto. In Orangeville there's a wonderful organization called an ALS support group, completely self-funded, in which they provide advice to people, they support people, they raise money for this organization, they do whatever they can to assist not only the people that have succumbed to that disease, but also assisting members of the family in all kinds of things. I support the group myself, in whatever way I can, in whatever limited time I have.

I make that statement as an example of a volunteer group that works. There are all kinds of groups that work around this province, very dedicated people who will do almost anything to assist people. Many of them have come to this committee.

So my question to you is—and your group, obviously, supports advocacy for cultural communities—in dealing with that aspect, can you tell me what role, dealing specifically with the cultural communities that you work with, can community agencies and volunteers play in addressing the advocacy needs of Ontario that are so badly needed?

**Ms Haniff:** My experience in dealing with the cultural community or the ethno-racial community is that there needs to be a lot of education, a lot of awareness, within those groups, even to provide the services that they need to provide. With the dismantling of the Advocacy Commission, which body is going to provide that sort of education?

ERDCO has worked very closely with the Advocacy Commission in doing that public awareness to our members and members in our community, and we find that we really value that relationship and it was very helpful to us.

In terms of volunteers, volunteers have a role to play,

but they're not enough. We're all in the community competing for funds, and you're saying that specific group is self-sufficient.

**Mr Tilson:** I qualify that. They're fighting like everyone else to raise money, but they are self-sufficient. They work very hard to raise money, and they continue to raise money throughout the year.

**Ms Haniff:** And so are the other groups.

**Mr Tilson:** Yes, they are.

**Ms Haniff:** And who are they getting the money from? The same people. Now there's going to be less money to go around.

**Mr Tilson:** I think we've got an obligation to assist people who need help. We all do. You do; I do; and that's the role. We can't count on the government to do everything in our lives. I can tell you that I personally support this particular support group because, obviously, it affected me personally. But I can tell you I didn't count on the state to help me.

**Ms Haniff:** But if the state has power, if the state has control, the state has a very, very important role. They affect our lives.

**Mr Tilson:** Yes, they do.

**Ms Haniff:** They determine whether we live or die. So it's very, very important. You have a lot of power.

**Mr Tilson:** Let me ask you another question with respect to families and the role of families. What role do you see that families and friends can play in assisting people who need assistance?

**Ms Haniff:** Okay, number one: Not everybody has families and I think we keep forgetting that.

*Interjection.*

**Ms Haniff:** And the second thing: The families are the abusers sometimes, in a lot of the cases. For our community, ethno-racial people with disabilities, their families are not even here. They're alone in the hospital. They have no one. As for friends, we don't have friends. The people in our lives are people who are paid to be there. We are placed in some very, very difficult situations.

**Mr Tilson:** Thank you very much for coming and providing your comments to the committee.

**The Vice-Chair:** We'll move on to the official opposition now and Mrs Caplan.

**Mrs Caplan:** Thank you. I think it's clear that the government plans to repeal the Advocacy Act and, frankly, I don't think there's anything that anyone's going to be able to say to them to change their minds, that was part of their campaign platform—

*Interjection.*

**Mrs Caplan:** I'm glad you raised that, Mr Tilson, thank you. We said that in fact we would scrap the Advocacy Commission as it was constituted by the NDP, but we believe the act could be fixed and that it did not have to be repealed. We never said we would repeal the whole act, so I'm glad you gave me a chance to clarify that.

**Mr Parker:** That's not what the candidate said in York East.

**Mrs Caplan:** I can tell you that's what was in our literature.

**Mr Bernard Grandmaître (Ottawa East):** Are you doing what your Common Sense Revolution said?

**Mr Garry J. Guzzo (Ottawa-Rideau):** Guaranteed

then, and you know it.

**Mrs Caplan:** The reality is this debate today is about what you're planning to do and I think it's important that we accept the reality that that's what they're going to do. My question is, given that reality, can you see any opportunities through the existing legislation, the consent to treatment legislation, to put in some foundation services via amendment that would protect some of the components of advocacy? Have you thought about that?

**Ms Haniff:** I haven't looked at the other legislation and looked at it that way. Our main focus was the repeal of the Advocacy Act itself, but we know that legislation would not be able to stand alone; it needs the Advocacy Act to support it.

**Mrs Caplan:** The fact that the Consent to Treatment Act eliminates the need for any rights advisers, except for under the Mental Health Act—and we were unclear as to how the government intends to move to even provide that outside of the psych hospitals—the notion that hospital administrators will be able to appoint advocates but there's not going to be any consistent training of the rights advisers or those who would act in an advocacy position, although not a formal advocate, I think is of concern to a lot of people.

I believe that the Consent to Treatment Act could be strengthened to include some of those provisions. If you'd like to think about that, there's time over the next couple of weeks to submit something in writing. We're looking at possible amendments that hopefully the government would consider that would at least allow for a foundation that wouldn't see the clock turned back entirely. Thank you.

**The Vice-Chair:** Any other—you've still got about three minutes.

**Mrs Caplan:** If I have time, thank you. The question that I've been asking everyone: Was your group consulted in any way during the development of the new legislative changes?

**Ms Haniff:** No.

**Mrs Caplan:** Since formal rights advice and advocacy is being eliminated in everything other than the Mental Health Act, my belief is—and I want to know if you agree—that as a minimum, there would be an obligation for those professionals who act as evaluators and assessors in the determination of capacity to inform the person that they have been found incapable and let that person know that they have a right to appeal. That is an obligation under the Mental Health Act and it's an obligation of the public guardian and trustee's office. My view is, as a minimum, it should be an obligation under this act for anyone who makes that determination.

**Ms Haniff:** Yes, I would support that and I think it's very important that the dignity of people with disabilities is not taken away, not stripped away from us. I think that's a very crucial point.

**Mrs Caplan:** Thank you very much.

**The Vice-Chair:** Thank you very much, Ms Haniff. We're going to move on to our next group. I want to thank you on behalf of the committee for your presentation.

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## HOSPITAL FOR SICK CHILDREN

**The Vice-Chair:** We'll call upon Dr Christine Harrison and Dr Alan Goldbloom from the bioethics department at the Hospital for Sick Children. Good morning. You have 30 minutes for your presentation and you can begin any time.

**Dr Alan Goldbloom:** My name is Alan Goldbloom. I'm vice-president of the Hospital for Sick Children and really here to speak on behalf of the hospital. I'm accompanied by Dr Christine Harrison who is the director of bioethics at our institution and who has been involved very much in the education of our own employees around the existing Consent to Treatment Act and certainly in our discussions of proposed changes.

My purpose is to speak today in strong support of the important changes that are embodied in the Health Care Consent Act. It was almost four years ago that I presented a brief to this same committee, then differently composed, on the proposed Consent to Treatment Act, and at that time I outlined some of the major concerns of those involved in child health care. Despite the amendments that were made following the committee hearings, many of the initial concerns that we had were not addressed and the act was ultimately proclaimed.

At the Hospital for Sick Children, we dutifully began an educational process for all of our staff led by my colleague Dr Harrison. The predicted deficiencies of that legislation and the almost impossible task of practical implementation have led to confusion and difficulty in our institution. More important, we've seen no evidence that our patients have been better served. Indeed, when the provisions of the act have come into play, the opposite has been true.

It had seemed from the beginning that development of the Consent to Treatment Act arose out of some very genuine concerns about the rights of incapable and vulnerable adults, particularly the aged and the mentally and physically incapacitated. It was clear to us that children were never the primary focus. Indeed, the law already provided protection for vulnerable children through the Child and Family Services Act. Nevertheless, children from birth onward were swept up in the same legislation.

It's always been our position that a child's maturity and independence evolve over time and don't occur on a specific date. Our society views a child as a part of a family and generally accepts that the parents speak on behalf of the child. In health care, we also recognize that children participate increasingly in decision-making about their health care as they get older. When conflicts occur, they usually get resolved in a consensual process that involves the child, the parents and the caregivers. Regrettably, the Consent to Treatment Act tended to put these three parties in adversarial positions—a giant step backwards.

It would be our goal to foster independent decision-making as children mature without imposing a complex and legalistic bureaucracy which may interfere with family and caregiver support.

My comments today will be limited almost exclusively



to the Health Care Consent Act and are derived from three sources: first, our observations and experience with the implementation of the Consent to Treatment Act at the Hospital for Sick Children; second, the results of a qualitative study consisting of an interview administered over the summer of 1995 in the hospital to a sample of paediatricians, paediatric surgeons and a child psychiatrist; and third, observations and feedback on the new Health Care Consent Act provided by various groups and individuals from within the hospital.

I'll address the following areas: the age of consent; the substitute decision-making process; the appeal process, including rights advice; the Consent and Capacity Review Board, and the scope of consent.

First, about age of consent, neither the Consent to Treatment Act nor the proposed Health Care Consent Act states an age of consent, and we are in agreement with that position.

Children develop in stages, as does their decision-making capacity. With no stipulated age of consent, we may assess the level of maturity and independence of each child and include them in a decision-making process to the appropriate extent. This allows for mature, autonomous adolescents to give or refuse consent to treatment on their own behalf and perhaps without parental knowledge.

Having no age of consent, for example, allows us to treat the 14-year-old who has a sexually transmitted disease who would not have come for treatment if he or she thought that the parents would be informed. Our adolescent medicine clinic in fact regularly deals with serious health problems that some teens refuse to bring to the attention of their families or even their family physicians. Our ability to recognize their autonomy in some areas allows us to win their confidence and to provide treatment and counselling, not to mention the direct impact on health. The lack of a legislated age of consent allows us to recognize that children are persons, and thus individuals. One particular 15-year-old, for example, might be very dependent on his family and immature, while a different 13-year-old might be very independent and mature.

Paediatricians whom we interviewed supported this aspect of the Consent to Treatment Act in that it resulted in treatment alternatives being presented in a less biased way and in the increased participation of children in decision-making. As one of our paediatricians said when asked if she thought there should be an age of consent, she said: "No. It's a relic." So we recommend that no age of consent be included in the Health Care Consent Act.

On the subject of substitute decision-making, those making decisions for children must do so based on a calculation of their best interests. This is a concept with which paediatric health practitioners are very familiar and experienced, and we believe the guidelines for substitute decision-makers in the Health Care Consent Act, which have been clarified somewhat from the Consent to Treatment Act, are helpful.

We also appreciate the new distinction in the hierarchy of substitute decision-makers between a parent who has custody of a child and one who has the right of access only. In cases where parents disagree, this allows us to

turn to the custodial parent for a decision. This in fact is a very real and frequent issue in our hospital, where many children have parents who are separated or divorced and whose situations are sometimes less than amicable. The ill child sometimes becomes the focus and victim of the parental conflict. We need clear direction regarding the rights of the custodial parent.

We also strongly support the elimination of the requirement for a formal family member statement, as had been required in the Consent to Treatment Act. The original legislation required that family members who are consenting for incapable relatives make a statement as to the appropriateness of their giving or refusing consent. This just didn't make sense in our setting. It was confusing for parents and it required an unreasonable use of our staff's time. If you can imagine, we have about 200,000 clinic visits a year and the requirement was that each time a formal statement be given, either orally or in writing. In practical terms, this meant that every mother with a babe in arms would have to make a statement to the health provider that she is indeed the appropriate and legally delegated substitute decision-maker for that infant. I'll make a bold confession to you here and tell you I don't think that we as an institution have been in compliance with the letter of the law on this, nor was there any practical or reasonable way for us to do so.

One problem we face from time to time has not been resolved, however. Sometimes we see parents who are incapable of making decisions for their children, either because of their cognitive abilities or a temporary condition such as alcohol or drug impairment or because we're unable to contact them or other family members for decisions. In cases such as these, we've had difficulty in determining who should make decisions for the patient. This is under the current legislation.

In one situation, both the children's aid society and the office of the public guardian and trustee declined jurisdiction while a newborn infant waited for surgery in the neonatal intensive care unit. A judge had to resolve this particular situation, but we would request that the proper decision-making authority in such cases be clarified and reflected in the Health Care Consent Act. Our preference would be that the children's aid society would be the appropriate decision-maker in these situations, as they are more experienced with the needs of children than are those in the office of the public guardian and trustee.

Our recommendations: We support the changes which give priority to the custodial parent, over the parent with access, as a substitute decision-maker; we support the elimination of the requirement for a formal family member statement required in the Health Care Consent Act; and we recommend that the Health Care Consent Act specify that in the case of incapable children, the children's aid society should be the substitute decision-maker of last resort when there are no capable family members available or willing to act.

The existing Consent to Treatment Act prescribes a complicated and legalistic process to be followed if a child aged 14 years or over is found to be incapable. This process includes notifying patients that they have been found incapable; providing children with written notification of their right to meet with a rights adviser and a



review board hearing when requested. The Health Care Consent Act has improved this process.

First, rights advice: These requirements really introduced an adversarial atmosphere into the relationships between patients, their families and the health care providers. It is rare that we cannot rely on parents to be advocates for their children. In supporting the removal of the rights advice process, we are not advocating that such children be kept uninformed or uninvolved. Instead, we want to enhance and enable the existing supports which help children and families deal with difficult choices, uncertainties and decisions. This change will allow families to work through these issues with their children.

Under the existing law, if an incapable 14-year-old says no, even to a needle or an injection, then the rights advice process comes into play and the parents are immediately removed from the loop. The reality for those of us in health care is that teenagers say no initially to lots of things, but after discussion with parents and caregivers the situation is usually resolved. We therefore support the removal of the rights advice process from the Health Care Consent Act.

1150

I might add that many of our staff feel strongly about the importance of patients being informed about their rights when genuine conflict occurs, and plan to consider developing a policy in the hospital regarding this matter. I might also add that most of us who are guided by our professional ethics feel equally strongly that this is something that doesn't have to be included in legislation, but something to which we are bound by the ethical guidelines by which we practise. We support the removal of the rights advice process from the legislation.

On the subject of the Consent and Capacity Review Board, we've had several experiences with this board, the first occurring just a few days after the Consent to Treatment Act was proclaimed. I believe it may be instructive for you to know just how our hospital was impacted.

The first episode involved an adolescent patient with life-threatening anorexia nervosa. Her parents were desperately seeking treatment for her anorexia, but the patient objected. Upon being notified of her rights, she proceeded to challenge the finding of incapacity through the review board. This patient's condition was so precarious that a resuscitation cart had to be kept just outside the hearing room, which was our hospital boardroom. This weak, very thin patient attended the hearing wrapped in blankets, connected to intravenous and attended by a nurse.

Attending this hearing were the patient and both her parents, three members of the review board, a court reporter, two paediatricians, a psychiatrist, two other physicians involved in her care, three nurses, a dietician, the hospital risk manager, a hospital program administrator, our director of bioethics, and finally the patient's lawyer, the paediatrician's lawyer and the hospital's lawyer.

A hearing that was expected to last an hour or two took the entire day. It was like a trial, with each party, the patient, the patient's parents and the paediatrician presenting evidence, calling witnesses, and examination and

re-examination of each of the parties and their witnesses by the patient's legal counsel, the paediatrician's legal counsel and each member of the review board. In the end, the board upheld the physician's finding that the child was incapable, but this finding was appealed, resulting in yet another process that was very costly in staff time, physician time and legal fees, and that appeal was unsuccessful.

We found the process complex, costly and in at least one case compromising to a patient's health and well-being. While it's important that persons who've been found incapable have the opportunity to appeal that finding, we believe that the process should be more consistent with the ethos of the health care setting rather than the legal arena. We've been assured by the chair of the Consent and Capacity Review Board that they are working to make their procedures more user-friendly and efficient, and this is reflected in the changes to the review process found in the Health Care Consent Act.

A somewhat different concern was highlighted in the second hearing at our hospital. In this situation we had a 13-year-old child with a serious life-threatening illness. The custodial parent refused to allow necessary lifesaving treatment on religious grounds, and the child verbally agreed with the parent. Because our physicians deemed the child incapable and because the care was being refused by the parent, the children's aid society stepped in to take custody. As is routine in such cases, the matter was taken before a family court judge, who granted custody to the CAS. In this situation, the child's legal counsel used the Consent to Treatment Act as the basis of a challenge to the judge's ruling, claiming that this was a matter for the Consent and Capacity Review Board and not for family court. Fortunately, the board agreed that family court was the appropriate venue for this matter. We believe that in future any such confusion and duplication could be avoided if the Health Care Consent Act stipulates who has jurisdiction in such cases.

We support the changes to the composition of the consent and capacity board and the changes which will allow it to function more efficiently. We recommend that the consent and capacity board and family court's respective jurisdictions be clarified in the context of capacity to consent to treatment.

Section 11 of the new act broadens the understanding of consent to a treatment so that it includes variations or adjustments in the treatment. This is a particularly welcome and important change for patients in hospitals. Strict interpretation of the prior or existing act led some of our staff to believe that a new consent would be required every time a treatment was changed, including a minor change in antibiotic dose, minor changes in medication, institution of physiotherapy and so forth. In most acute care hospitals, some elements of treatment will change for most patients on an almost daily basis, and an initial consent must be inclusive enough to allow reasonable day-to-day function. We therefore support this change.

Section 12 of the new act allows one health practitioner to propose a plan of treatment on behalf of all the health practitioners involved in the plan and to make a determination regarding a person's capacity on behalf of



all the health practitioners involved in the plan. Again, this is a very positive change for those of us working as parts of multidisciplinary teams. Anyone who has been a patient in an acute care hospital knows that multiple caregivers are involved. Under the existing Consent to Treatment Act, many of our professionals felt that each had to obtain separate consent before they could participate in care. This was simply not a practical option in such a setting.

We support the changes which affect the scope of consent and its applicability to all health care providers involved in the plan of treatment.

I will not read the summary, which is simply a collection of the recommendations or suggestions that I've already listed, but I'd be happy to answer questions, as would my colleague Dr Harrison.

**The Vice-Chair:** Thank you, Dr Goldbloom. We'll start off with the Liberal caucus. We'll be looking at about four minutes per caucus.

**Mr Grandmaître:** Doctor, you would support no-age consent, and you did confess to us that it was impossible to abide by the present legislation to the letter. How would this no-age consent facilitate your work?

**Dr Goldbloom:** First, just to clarify, my comment about not abiding by the letter of the law was related to one specific aspect, the family member's statement that you are speaking on behalf of the baby that you're holding.

As far as no age of consent, what that allows us to do, and in fact we have always functioned this way, is to recognize maturity when appropriate. It allows us to say to that 14-year-old, who either is very mature and appropriate or who may even be independent of his or her family, we recognize that individual's independence. It in no way prevents us from involving the family when it is appropriate to do so. In fact, the majority of teens we speak to want their family involved and we're happy to do that. It's in those circumstances when they don't and when family involvement may be an obstacle to care that we need that opportunity.

If I can just relate one brief anecdote about that. When the original consent-to-treatment legislation was coming in, I participated in a radio open-line show on this topic and was answering questions. One of the issues that came up was, if a teenager was part of a program like a measles vaccination program in school and if he refused to participate, what was the parent's situation then, because teenagers were regarded as independent? It was interesting that several teens called in and they all said: "There's no way I would ever allow anyone to give me a needle. Therefore, I'd want my parents to make the decision." In other words, on the one hand they're independent on some things; on the other hand they recognize that there are certain things they want their parents to decide for them. I think this allows us that flexibility.

**Mr Grandmaître:** Thank you.

**The Vice-Chair:** We'll move now to the NDP caucus. Mr Marchese.

**Mr Marchese:** Thank you for your presentation. I have, hopefully, two quick questions and my colleague has some too.

With respect to substitutes no longer having to make

a statement, the Psychiatric Patient Advocate Office agrees with substitutes having to make a statement. I think it's done so as to protect and respect that particular individual who may not have the kind of family that we would all love. It is done as a way of making sure that those people who make the substitute decision understand their obligation. So they make a statement and they talk about their relationship. Number two says that the relative has no reason to believe that the patient, when capable, would have objected to the relative acting as an SDM and that there's not a higher-ranking relative who is available.  
**1200**

Is that too onerous, do you think, as a way of protecting that individual and as a way of having that other individual understand their obligation? Is this too onerous?

**Dr Goldbloom:** My feeling is that it becomes onerous if it's applied across the board of all health care encounters. I would add that we still, as an institution or as an individual health care provider, are obliged to be comfortable, if you will, that the person who is speaking is the appropriate person, as we've always done—if a parent signs a consent to have the child examined and so forth.

What we objected to was the formalization, this requirement of making a statement at every single encounter, either verbally or in writing, having to sign this statement which in actual health care practice, in routine practice, became impractical. I don't think we are for a moment relieved of the obligation to ensure that the person who is speaking on behalf of a patient is authorized to do so.

I don't know if you want to add anything to it.

**Dr Christine Harrison:** I would like to.

First, I guess there are other parts of the Health Care Consent Act which distinguish between psychiatric settings and non-psychiatric settings and perhaps that could be a distinction that would be made where it might be required in one and not the other.

The other thing is, the wording that you quoted indicates what the problem was, that a person has to make a statement that the person would not have objected to them making the statement when they were capable. To say that to a parent of a newborn just makes them go: "What? What are you talking about?" It was very confusing and distressing for some of them.

**The Vice-Chair:** We have time for one more quick question from Ms Boyd.

**Mrs Boyd:** I want to tell you how delighted I am that you've pointed out the problem around the children's aid society and the family court and their jurisdiction. I certainly hope that we can incorporate your suggestion into any changes on the rights advice issue. I understand the problem as you see it and really appreciate what that portends.

You made a comment that it would be in any case incumbent upon the professional to make sure that the person knew their rights. We've been pressing professionals who have come before the committee, including the College of Physicians and Surgeons, as to how you would accomplish ensuring that was an obligation on the part of the physician or in some cases the nurse, any of the other registered helping professions. I wonder if you could tell



us how, from a consumer point of view, there could be some real sense of confidence that in fact that obligation would be carried out and if it wasn't carried out that there was some sanction.

**Dr Goldbloom:** Maybe I can make a comment and my colleague Dr Harrison may wish to as well. I think first of all, ethically, we all feel that patients should be informed. So if a decision is made not to recognize an individual as being capable, particularly a teenager, for example, and that we are going to turn to someone else for a decision, I think it is incumbent upon all of us ethically to be able to notify that individual.

In terms of outlining for the individual a list of all of the rights and options, whether that is the obligation of every care provider I'm not sure about. When people have objected or protested or disagreed with the caregiver, it seems to me that people are quick to find out about options, as in the increasing numbers of lawsuits and other protests and so forth.

There are also mechanisms that hospitals are starting to provide, increasingly. We have a patient representative office in our hospital, and that individual really serves as a patient advocate. Many large hospitals have seen this as part of their mission and something that they should provide. I think that the provision and the support for that kind of information is far more sensitively done and more practically done within those kinds of arrangements than through a rather blunt instrument of legislation.

**The Vice-Chair:** We're going to move to the government side. I've got two speakers here, Mr Tilson and Ms Johns. Mr Tilson, do you want to go first?

**Mr Tilson:** I have one question and then Ms Johns has a subsequent question.

I found your report very concise and very thoughtful, but the one comment that I'd like you to elaborate on has to do with the issue as to who should be the substitute decision-maker of last resort when there isn't a parent available or capable to make decisions for that child or young person. You have recommended that your preference would be the children's aid society, and you've given an example of a problem, as opposed to the official guardian and public trustee. It's an interesting suggestion, and I'd like you to elaborate as to how you reached that conclusion.

**Dr Goldbloom:** I think this is based on our experience and perhaps on a recognition of the children's aid societies' familiarity because they are delegated by law to act in the interests of children in need of protection. They usually have the infrastructure, the staff and the experience of dealing with children in these situations that we feel that they can handle them efficiently and well, so that under existing arrangements that seems to us to be the most appropriate body.

If somehow the public guardian was prepared to take this on and become acquainted with all this and somehow reorganize, I'm not saying that there couldn't be another option, but certainly our experience has been that the children's aid society is very experienced with this and deals with it efficiently and well. Christine, do you want to add anything?

**Dr Harrison:** No.

**Dr Goldbloom:** That was the basis for it.

**Mr Tilson:** I understand that. Thank you.

**Mrs Johns:** Under the Health Care Consent Act, one of the things that has happened is that low-risk treatments have been removed from the auspices, the control of the act. We've had a lot of comments about that over the last two days. Would you comment on why you didn't comment on it?

**Dr Harrison:** Some of us did.

**Dr Goldbloom:** I think, in fairness, some of the feedback that I had from some of the professionals in our organization questioned whether the law was giving too much leeway to professionals in making that statement. I guess this was an issue where there was a lot of discussion.

My own feeling, again, is that this is something that is better handled by professional guidelines, professional ethics, than it is by, as I say, a relatively blunt instrument like legislation, because almost everything that we do is subject to some form of interpretation, a decision about what's risky, what's not risky and so forth.

If a child comes into the emergency room with a cut and is waiting to be assessed and treated by the caregivers, is it reasonable for the nurse to provide a little dressing, a piece of gauze over it, or does that become something for which a consent has to be obtained? Can Tylenol be given to the child who has a fever and is waiting to be examined to determine the cause?

Those kinds of decisions have always been within the scope of professional judgement and professional practice. We've had to rely on them in the past. When people have felt that we've exceeded them, the College of Physicians and Surgeons comes into play with its guidelines, or the civil code comes into play. I think that there are instruments available to deal with abuse, but I don't think it belongs here.

**Dr Harrison:** I'd like to say something about that. Dr Goldbloom and I had to decide what we were going to talk about and what we weren't going to talk about, and that was just one thing that we had discussed as an issue and felt we wouldn't have time to discuss. But I'm glad you brought it up, and I'll just maybe pass on a couple of comments from some of the groups within the hospital and also other bioethicists whom I work with.

Two comments: One is that I'm not a lawyer but we really don't understand the need to specify some exceptions to treatment at all in the legislation, because my understanding is that one still has to get consent under the common law. In the Consent to Treatment Act you would have to look at rights advice and so on, so there would be a reason for making some exceptions to treatment, but we don't really understand the distinction in the Health Care Consent Act.

The other thing is, as a sort of exercise when I was going around discussing the new Health Care Consent Act with people in the hospital, I asked them to give me some examples of things that they thought would be a treatment of little or no risk of harm. I got the whole range of responses from people: Tylenol, first aid. One paediatrician said a lumbar puncture, which is a spinal tap, in some circumstances might be something of little or no risk of harm. At one session that I went to, a physician and a nurse both agreed that this might allow



a surgeon who was in the middle of surgery and who found something he wasn't expecting to find, to take care of that problem while he was in there. I think that isn't what's meant in the law, and maybe if that phrase is going to be included it needs some word changing.

**The Vice-Chair:** Mr Guzzo, I apologize. We're not going to have any time for any more questions. Dr Harrison and Dr Goldbloom, I want to thank you very much on behalf of the committee for your presentation. We will be adjourned until 1 o'clock.

*The committee recessed from 1210 to 1307.*

#### GEORGE GRAHAM MAINER

**The Chair:** It is now 1:07 and I would like to call the committee to order. Our first presenter is Mr George Mainer. We've discussed the matter. You have one half-hour, including questions. If you would proceed.

**Mr George Graham Mainer:** I will try to read quickly so that the entire thing will be done, and then take questions.

This is a case study of medical ethic, not in relation to whether a medical problem is caused by the digestive system or the vagus nerve, not that at all, but ethic in the broadest sense.

Here are some notes dealing with two individuals primarily concerned, Joram G. and Chris Horne. We deal with each of these in turn.

(1) Joram G.: A prominent lawyer, Mr G was charged at the end of February 1994, with a few dozen others, with being a ring of narcotics distributors. This is called the "G ring" hereunder.

Covering the period July 8, 1991, to October 5, 1995, some 221 weeks, three subsets are:

(a) July 8, 1991, to February 28, 1994, 138 weeks, in which the most powerful criminal forces, cloaked in the borrowed robes of law and order, used the manifold instrumentalities of Canada's federal, provincial and municipal levels to harass me; and

(b) March 1, 1994, to a day in March 1995, during which my most innocent comments were silenced by claims that I was trying to deprive Mr G of a fair trial; and

(c) April 1995 to February 7, 1996, today, in which I have endeavoured to articulate this report despite vicious attacks.

I was the person who made the connection between Joram G. and the Franklin Group—called "FG" hereafter—in this way:

About 1325 hours, Wednesday, July 10, 1991, I noticed that my above-named telephone line—416-972-0975—had 365-1968 as the last number to call. I traced this call through Bell Telephone. At 365-1968, a lady answered with "Franklin Group" twice, because I asked her to repeat it, and she told me that since it was Mr G's private line, it must have been Mr G who wanted to speak to me. She gave me Mr G's number as 361-3178. Dialling this number gave me access to his answering machine, which gave me his number as 365-1967. The traced call was to FG's private line at 365-1968, though the FG listing is 365-1966.

From the Law Society of Upper Canada, I learned that

G and Associates at 50 Richmond Street East, Suite 500, Toronto, M5C 1N7 had telephone number 365-1966, so that the link to FG was based on a wrong answer at the traced number 365-1968.

At length, I reached a stranger to me, Joram G, who did not realize that I knew his connection to FG during contact by telephone early in the afternoon of July 10, 1991. He told me that I "go around photographing people," and invited me to go to his office at 50 Richmond Street East and photograph everyone there. He also undertook to find out who had phoned me and get back to me as soon as possible, taking my name and phone number. He volunteered that the person who answered my phone call was "Cindy."

I did not reply to his question, "What do you do?"

While Joram G was investigating who telephoned me from 365-1968, I sorted out the 1991—not 1995—numbers, and if I may just have your permission to skip down to, on the next page: "To this day I do not know who phoned me."

It is evident that Cindy gave me the connection, not evident from the 1991 phone book, between G and FG.

Cindy also focused attention of the G ring on George Graham Mainer, the undersigned, as the other side of the coin who in July 1991 was aware only that a prominent lawyer had a very strong animus against him. My initial impression was written down on July 11, 1991: "My photos of faces on street must hurt the Mossad, hence Joram G's telephone call from the Franklin Group, 365-1968, which was the identity given by the person Cindy (says Joram) who answered the phone who said 'Franklin Group' and who identified Jay G as the person who'd have done it."

I just wish to point out that all of that is incorrect because of the secrecy involved.

My allusion to the Israeli intelligence Mossad is probably based on my having photographed the man whom I have for 20 years assumed to be a KGB operative on July 8, 1991, along with 35 other snapshots taken to Black's on July 10 and picked up shortly after noon on July 10, 1991. These street photographs were quite innocent. For example, on July 12, 1991, I photographed an accident on Bathurst just south of the 401 between Honest Ed's Lincoln Town Car and a station wagon that was making a left turn. I gave my only prints of these photos to the doorman at 33 Rosehill, Edgar, whose true name I learned from his obituary.

In sharp contrast to my innocent behaviours, there were several menacing interventions.

I'll just skip down to a photograph taken of me. I now think that Joram G had a photograph of me from July 14, 1991, but I have not been able to obtain a copy of this photo despite several requests to Mr Wilson, whom I do not otherwise know. But in 1991, I had a very positive opinion of that young couple.

Several weeks later, my Spanish ex-psychiatrist put himself in the G ring when he described himself as "with Joram G," while I explained to him how one delineates a structure and forces it to function: delineating a structure and forcing it to function. Please see the third paragraph of Staff Inspector L. A. Bruce's letter to me dated January 29, 1996, for a textbook example of the

staff inspector delineating the structure.

This structure functioned to portray my simple itinerary as a criminal act. Then the psychiatric structure functioned to cover up identities of the true criminals. The new doorman replacing the late Edgar Vaivers, John Hunter, acting as my voluntary informant, had given me the information about the licence plate of a bearded man who arrived in one set of clothes and left in another after about an hour's visit to Ms Knox's apartment. This informant and I shared a desire to identify sources of radiation.

Please bear with me. It may seem to be superficially funny but it really isn't. It's a very meaty case.

The structure of neighbours, though at various times floor captains of tenants' associations dominated by Chris Horne are classed in the G ring if the ethic is especially feculent, partaking more of the cocaine trafficker than the thief. It's a judgement call. Their advent, uninvited, into my life so soon after my skirmish with Mr G forces me to label the structure with his name. Dr P, Ms Nowell and Ms Knox are members of several structures that have adverse effect on me.

On Wednesday, July 17, 1991, a neighbour, Ms Knox of 2602, mentioned a circular letter about security problems in our residential complex of 629 apartments. The bottom line is that they functioned as a structure with Ms Nowell and it implies that both are members of the G ring.

In subsequent years, attacks using gas and radiation emanated primarily from 2602. I noted very many distinct incidents during the period. On occasion, after I got my peep-hole, I caught Ms Knox and on other occasions Malka Rosenberg (Malro Co, in whose apartment I met Ian Scott), playing with my letter slot, sometimes accompanied by noxious odours.

In order to pinpoint radiation, I bought a detector from Spy Tech and used markers to circle the spots on the walls with 2602, where on March 25, 1994, very powerful radiation was detected using this radiation detector. The date is thought to correlate with events in the life of Joram G or Chris Horne.

Because I was getting nowhere with my complaints to my landlord, I started to phone Ms Knox's employer, first at Sick Children's Hospital, then at Mount Sinai. They were sympathetic but ineffectual. On August 22, 1995, I phoned 911 just prior to 2200 hours, with this result obtained from the Metropolitan Toronto Police Force:

"Operator: Emergencies, 51 and 53 division.

"Me: Yes, I've just been hit with, zapped with some kind of deliberate electronic assault from, I believe, a neighbour."

Please let me skip down; it's quite tautologist. You have it before you.

She says, in a very insulting tone—I have the tape if you want to hear it. In a very insulting tone, she says, "Are these aliens?" In other words: "You are an inferior. You, Mr Mainer, are an inferior, so I'm saying to you, is it possible that these are aliens, some kind of mystic interpretation?"

On October 5, 1995, I wrote and delivered by hand letters to some 28 addressees. My itinerary is shown below and cannot possibly be described as following an

even now unidentified friend of Ms Knox, though I think he is the psychiatrist Peter G. S. Would you please rub out T-E-N-N. Please rub out his whole name so he is described as Peter G. S. I didn't want—that's the result of a—let me continue.

Here is my itinerary on October 5: 12:30 to the Canadian Civil Liberties Association; 1300 to City Hall; 1320 to Chief Boothby and other people at 40 College; 1330 to the College of Physicians and Surgeons of Ontario; 1340 Queen's Park, one of my few replies. I received only two replies. One was from the Premier of Ontario. My hat's off to him for replying to mail that other people simply dismiss as ridiculous or criminal. Then 1400, Mount Sinai Hospital, Eva for Dr B. Smith plus "one unplanned." "One unplanned" is the man that we have been trying to identify. He is the man that I'm accused—that I'm cautioned not to criminally harass. Here's who have tried to find out: the police, Mount Sinai Hospital. No one can find out his identify. I am going to suggest one to you. But to continue, at 1425 to Metro Hall and at 1435 to the Globe and Mail.

I tried to learn the identity of "one unplanned" from Eva, whom I had asked on October 5 to remember him. So there I am up in Mount Sinai, having been given the runaround as to neonatal, perinatal, newly born etc. I finally find a Dr Smith, at least his Eva, and this man then intervenes on me. He jumps on me, so to speak, verbally. So I say to Eva, "This man"—I asked him: "Who are you? Please identify yourself." He refused. So I said to Eva, "Eva, will you please remember this man?" And so that's what that sentence is about. I had asked her on October 5 to remember him. These are the names mentioned at 1400 hours of the above itinerary, just to help you interpret that table. Eva told the third party, the third party that I had appealed to to help identify this man, the police having failed, the Mount Sinai Hospital having failed, so I asked a third party, Miss RW, I hope you won't ask me to identify her, that the man—Eva told the third party that the man was not bearded and sounded like a lawyer.

This RW, who is very familiar with medical investigations, phones Eva and says, "Eva, remember the man who told you to remember the bearded man?" I'm sorry. She phones and asks for the identity of the bearded man. She asks for the identity of the bearded man and Eva says, "Well, he didn't have a beard and he sounded like a lawyer." Eva had identified me, not the bearded man.

**1320**

The third party told me from her experience this meant that the black-bearded "one unplanned" was either an important doctor whom Eva feared could have her dismissed or in fact her boss in the department. In short, an implied intimidation kept his identity secret in the hope that she will not be fired. Ms RW is a Rachel White, the investigations department of the College of Physicians and Surgeons of Ontario, and she told me that she could get into a lot of trouble if she did this. So I hope you'll respect her. In short, an implied intimidation kept his identity secret.

The College of Physicians and Surgeons, called Coll of P&S in the above table at 1330 hours, will accept a complaint about a doctor only if his name is used. So



there is the basic conundrum. Ms White says to me, "We will certainly accept your complaint about this person, the black-bearded man, provided you give us his name." I say to her, "I can't get his name from the police, I can't get his name from the Ontario College of Physicians and Surgeons, I can't get his name from Mount Sinai Hospital, so how can I make a complaint?" and she says she's bound by the rules. So I say, "I appeal to you, will you perhaps find out by calling Eva?" whom I had asked to remember who this man was. She then does this, and Eva has identified to her me, not the black-bearded man at all.

We're dealing here with the medical ethic. I'm sorry to say that, but we are dealing here with the ethic of doctors who make decisions under Bill 19 and under the legislation that it wishes to replace. They substitute decisions; they sure do. This is a case study of their ethic. Please take it as that. Look through the verbiage.

So the College of Physicians and Surgeons will accept a complaint about a doctor only if his name is used. Consequently, shortly after 9 o'clock on November 13, 1995, I telephoned the president of Mount Sinai and explained events and asked him if I could come to his office and go through his book of staff pictures so that I could pick out "one unplanned." He said he didn't have such a book but that he would none the less try to identify him.

I should have left it there, but instead I put it into a letter and took it to him. We agreed in the telephone conversation that Eva would be a good source of information and would surely feel secure with the president of the hospital. About three hours later I placed a letter into the hand of the president of Mount Sinai with the request that he stamp it "Confidential." He mentioned that his investigation would take time, and it certainly has. I have not received a reply to date.

Meanwhile, the structure of two psychiatrists and my nursing neighbour—the nursing neighbour is the person mentioned in the 911 call when I say that the radiation is coming from a neighbour. In my 911 call Ms Knox is the neighbour to whom I allude. So the structure, two psychiatrists, one P, the other S, and the nurse functioned to criminalize my tedious complaints—to them tedious complaints—about radiation and gas paid for possibly by conversion of the hospital's resources.

Indeed, in one of my phone calls in March or April to Dr Smith, he never replied to anything. I did mention, "Where would she get these rare and unusual gases except from your department or your hospital?" So the conversion there is a sort of conversion to their own use.

I truly believe that I had several lawful excuses to deliver my letter to Dr Smith, Ms Knox's boss at Mount Sinai, and that "one unplanned" had no lawful excuse to interfere with me. Nobody in Mount Sinai can identify him, it seems, nobody at all, not even the president. He doesn't have a picture or anything.

Ms Knox has induced her friends to violate one of the fundamental principles of investigation, namely, it is an abuse of process where one attempts to use the criminal courts and police in the manner described. But it constitutes a further voluntary, on Ms Knox's part, indicia that she is willing to manipulate resources that belong to the public. Knox fears detection. It is I who fear for my

safety.

Turning now to the other one, thank you for allowing me to speak freely to you on the ethic of medic. One often hears from medics about problems created by anybody's legislation on health care—Liberal, Conservative, NDP: they complain about all legislation on health care—but one rarely has a chance to observe the ethic of the medics making decisions regarding the health of their patients. I think your amendments in part III of Bill 19 will help.

A case study is presented to you here that starkly reveals the manipulative character of medical decision-making in a sense that includes making decisions about mental health in a context of destructive secrecy.

I display today only what I've been able to glean from medics myself, with no replies to my letters, despite verbal assurance on 13 November 1995. If it is incomplete, a destructive secrecy must be blamed. Please make it obligatory to inform patients in writing, not just verbally in consultations in which the medic can claim his lies are part of treatment. Something in writing could be shown to disinterested people.

I was told on two different occasions by my ex-psychiatrist that the radiation of which I complained was punishment on me for experiments done by an unrelated organization, the CIA, upon the wife of an NDP MP from Winnipeg a generation ago. How does this contribute to cure? On another occasion he told me that my future subjects were using radiation to control my mind. They are known for this kind of manipulation. Strange that I should be called upon to explain these when I did not create them. Both are now claimed to be false memories of my own creation. Were these given to me in writing, they could be judged now.

Attached are these conflicting statements from police, because I complained after Ms Knox had misused the criminal law to prevent me from complaining to her employers. I was phoned by this constable and it was investigated. It was turned from an investigation into an inquiry and then it was changed again.

(1) Public complaint form 6 with accompanying letter dated 11 December 1995 from Naseema Singh of central region's office of the police complaints commissioner, and he says:

"On November 21, 1995, that service"—the Toronto service—"requested that your complaint be classified as an inquiry rather than as a complaint of police misconduct. Attached please find a copy of that request form. You will note that consent has been given by the police to classify this matter as an inquiry."

The attached form 6 has consent "For the following reasons." These are the words of the investigating detective recommending that it go to one step beyond investigation, namely, board of inquiry: "The preliminary investigation indicates that the subject officer was in the lawful execution of his duties." That's the one that Ms Knox deceived, according to him. "There is conduct that could constitute misconduct."

The misconduct of the policeman is claimed by the investigating detective, and on the basis of the investigating detective's assertion that there is a basis for misconduct, the investigation is upgraded to an inquiry. Contrast



this to Staff Inspector Bruce's final paragraph. You have that in your hands:

"There is no evidence of misconduct on the part of Constable Redigonda. Therefore, pursuant to section 81 of the Police Services Act, your complaint has been reclassified as an inquiry." I don't understand that. It's in the letter. Please take the letter. The letter is right there in front of you, the entire letter.

Note here how my complaint about fabrication of evidence—I requested that he be charged under section 137 of the Criminal Code of Canada—by a police constable has not been passed on to lying medics. They won't even identify him. But it has been passed back to me, which itself is an act of criminal harassment of me by Mount Sinai Hospital, where I was repeatedly misinformed about the location of Dr Smith. "Go to neonatal, go to perinatal, go to this, that and the other." Then that was interpreted as following this man, who has apparently not even a ghost there. He has simply disappeared.

I was repeatedly misinformed about the location of Dr Smith, and then fell back upon Ms Knox's employer. They give a particular spin to that. For example, in Bruce's letter, "You again approached this person on another floor of the hospital." I was trying to deliver a letter to Dr Smith and was finally at his desk, manned by Eva, at which this black-bearded man imposed himself on me. I was reminded of Joram G's nearly hysterical question to me over the telephone in July 1991, "Who's your sergeant?" which communicated to me that he owned the sergeants and perhaps higher-ups. This question came to me from two other sources.

My complaint to the 911 operator on August 22 has never been investigated. The criminal element has introduced the red herring and the bloodhounds have enthusiastically pursued it. It is astonishing that Black Beard has not been positively identified by the police or the hospital, yet he must have shaped the bloodhounds' chase, and that's the medical ethic. I doubt if Black Beard is even a friend of Ms Knox, but she is the only fully identified player—the chain: John Hunter, the doorman; Black Beard, who seems to be a medic making decisions that could endanger members of the public, explicitly me.

1330

Secrecy in the use of such expressions as "acquaintance" in Bruce's letter as opposed to "friend" in public complaint form 1, so in public complaint form 1 the constable had said that I was criminally harassing a friend; then the investigation revealed, downgrades that to an acquaintance; next it will be just an imaginary event. This substitution is very important, because it obscures the identity of "one unplanned," the black-bearded man who does not belong to Mount Sinai because nobody there has identified him. It is left to a major suspect in a totally distinct case—radiation on me, itself a beautiful opportunity for obscuration by manipulative people with a knowledge of paranoia—to change the identity of her friend or acquaintance as well as these labels.

Medics' ethic is shown at every turn in this case. Do not let this case study be obscured by verbiage. Comment is that the spirit of Bill 19, parts III and IV, though a vast improvement on existing law, ought to be much stronger anti-fraud by all personnel: family, legal and even

medical. Part VI of schedule A is also very commendable, but it could be made stronger by substituting a verb other than "knowing," such as "suspecting" it is untrue. After all, you pioneered the privative clause in the 1940s. Why not innovate again in the 1990s?

This law should assume that people are being put away in psychiatric institutions in order to prevent embarrassment to family, for example, when a dozen or so of the relatives of Lady Elizabeth Bowes-Lyon, now the Queen Mother, were confined as mentally defective in order to prevent embarrassment to the royal family.

The presumption ought to be that someone is being murdered for gain. This is especially important in an age of assisted suicide. Recall that even the physician of George V states in his memoirs that Edward VIII authorized what we would today call dying with dignity, since nobody stands up and shouts the actual truth at the time.

We now come to the second part: Christopher Horne, the prominent Toronto financial consultant. Mr Horne has an extensive collection of antiques, Inuit sculptures and 18 paintings sought since 20 October 1994 by the receiver appointed by the Honourable Mr Justice Spence, Coopers and Lybrand, where Joel Price told me in January 1995 that he had all the paintings. They now confess that they're still looking for 18.

The order of 20 October 1994 contains a provision for judicial review of the diligence of plaintiff RBC and receiver. The order of 20 October 1994 was sealed by the Honourable Mr Justice Ferrier. In an order dated 31 January 1995 Mr Justice Spence explained the reason why the order ought to be made public again. Those who keep the files at 145 Queen Street West lost the order, but luckily a copy was found in my private files. I took it down to her and gave it to her, saying, "Don't lose it again."

On 25 November 1994, Coopers and Lybrand was appointed receiver in bankruptcy, as opposed to the other one, and have reported lack of cooperation from Mr Horne, about whom an article will appear in the March 1996 issue of *Toronto Life*. There are exceptional articles often written by Kimberley Noble.

Although the act set out in schedule A to Bill 19 has cured a perception of overemphasis on bureaucracy in the emergency room, problems that arise are much more subtle as in the Corbett case, October 1991 to October 1994, about which there is an article by McNish and Noble in the *Globe and Mail's* Report on Business for 20 November 1995.

I've spoken to the priest who visited Frank Corbett once a week to give him communion and to the doctor who noted that Frank Corbett did not know how to write a cheque to access his large bank account. Father McGill mentioned two Hornes, and perhaps that's the dilemma we're on now.

**The Chair:** Thank you, Mr Mainer, on behalf of the committee. Unfortunately, there is no time for questions or I'm sure a number of members would have them. But I can assure you your report will receive the attention it deserves and I thank you very much for attending today.

**Mr Mainer:** Thank you very much. I owe a great deal to this Legislature.

ONTARIO ASSOCIATION OF



## PROFESSIONAL SOCIAL WORKERS

**The Chair:** Our next presenter is the Ontario Association of Professional Social Workers. I invite them to come up to the desk. I would ask each of you who is to take part in the presentation to identify yourselves for the purpose of Hansard and I would remind you that we have one half-hour allocated to both your presentation and questions, and you can use the time as you see fit.

**Mr Dan Andreae:** Thank you. My name is Dan Andreae. I'm the president of the Ontario Association of Social Workers and I'll be presenting the report today. There are 11 recommendations the profession has to give you today. I'm joined by two experts, two colleagues who will be able to answer your specific questions in this area, and so if I could ask you to introduce yourself, Doris.

**Ms Doris Guyatt:** I'm Doris Guyatt and I'm a consultant now. I do training on this area of legislation. I have been employed by the Ministry of Community and Social Services and Ministry of Health for the past 22 years and I retired in the spring of last year. So I feel I have a stake in what's happening here because I spent literally the last four years of my life working on this legislation and I want to ensure that we preserve the best of what was done before, although I think that what has happened has been very helpful in your new legislation.

**Ms Cathy Clothier:** I'm Cathy Clothier. I'm the director of social work and discharge planning at the Riverdale Hospital and I have 13 years of health care experience.

**Mr Andreae:** First of all, to the credit of previous governments who worked hard on this to bring us to the point that we're moving ahead with legislation in this sensitive area, we're here to help facilitate that process with you.

You have the text in front of you of our recommendations, so what I propose to do is—we could spend half an hour just me reading this and you get tired of my voice, and we don't want that to happen. What I'm going to do is to highlight some of the key recommendations that we'd like to make to you and then have time for us to answer questions specifically you may have on the issue as we go along.

The Ontario Association of Social Workers welcomes the opportunity to offer our perspective on Bill 19. Historically, the social work profession has advocated for the decision-making of the vulnerable adult. The OASW, as I'll refer to us, is a bilingual membership organization that was incorporated in 1964. It is one of 10 provincial associations of social workers belonging to the Canadian Association of Social Workers, which in turn is a member of the 54-nation International Federation of Social Workers.

We have 17 local branches and three chapters across Ontario and we have approximately 3,100 members. The practising members are social workers with university degrees in social work at the baccalaureate, masters and doctorate levels who, in addition to direct service, practise at the policy, program and community levels.

The social work profession has mechanisms to ensure accountability in three specific forms: (1) membership in the Ontario College of Certified Social Workers, which

was established in 1982 and operates under the structures common to all professional colleges with stringent membership requirements, procedures addressing complaints from the public about social workers and disciplining members who violate professional ethics or competencies; (2) structures provided within agencies/organizations, for example, procedures and guidelines, quality assurance programs etc; and (3) contractual agreements provided with the non-publicly funded services, for example, employee assistance programs.

Social workers are on the verge of attaining their long-standing goal of legislation to regulate the profession in Ontario. Two letters dated October 30, 1995, and January 22, 1996, received from the Premier to this effect, have confirmed that government will move forward to enact social work regulation. We're pleased about that.

The relationship of Bill 19 to social work: What I can say is that many social workers are employed in health care settings—about 35% would be probably—and as part of the team of health care providers and are frequently called upon to consult on issues related to mental capacity, consent, family functioning and the identification of substitute decision-makers.

As well, social workers take primary responsibility in health facilities for discharge planning, including planning for admission to long-term-care facilities. They also form the second largest proportion of those trained as capacity assessors under the Substitute Decisions Act, second only to psychologists, which surprises some people, but it's true.

Traditionally, social workers have provided advocacy services, both individual and systemic, for patients and residents of health and other residential institutions. For all these reasons and because of their broader expertise with the more vulnerable populations in our society, children, those with disabilities, the developmentally handicapped, the mentally ill, the aged and families in distress, whom we work with every day. We're vitally concerned about the changes, therefore, in legislation being proposed in Bill 19.

### 1340

In summary, in terms of general comments, the profession is supportive of the amendments and new sections, including the streamlining of operational aspects of the act and facilitating implementation—assist families in taking advantage of statutory guardianship and powers of attorney to act on behalf of their incapable members; permit the setting of standards and the regulation of fees for capacity assessors; provide clearer definitions of treatment, treatment plans, and what constitutes a relative for the purpose of substitute consent; clarify the distinction between treatment and personal care services and the application of substitute consent provisions to both; clarify the issues around the age of consent and, finally, introduce a new system for admission to long-term-care facilities that provides protection for the elderly. On page 4 there's more.

We're also concerned—the list goes on: the removal of checks and balances that provide protection for the most vulnerable; the watering down of the right to information when the right to make one's own decisions about property, personal care, treatment and placement is at

issue; the substitution of volunteers for trained staff to give rights advice; the greater decision-making power given to health professionals; the complete removal of advice about the process of appealing a decision regarding capacity to consent to treatment and, finally, the lack of protection in particular for persons without families or with abusive families.

If we look then at specific issues, on page 5 of our document, we have in relation to witnesses a particular recommendation. It follows on page 6. The OASW, the profession, recommends that the Attorney General reconsider the deletion of the requirement that witnesses to the granting of a power of attorney have no reason to believe the grantor is incapable of giving a power of attorney for property or personal care and that some other way be found to facilitate the witnessing of these documents.

Our second recommendation under Compensation for Guardians, reads that the OASW, the profession, recommends that there be no financial compensation for services related to the provision of guardianship of the person or the exercise of a power of attorney for personal care.

Number three is a key area, because social workers have a lot of experience regarding volunteers and volunteering in institutions. Reading this out a bit more specifically, Bill 19 authorizes the public guardian and trustee to appoint volunteers to provide advice and assistance under the SDA.

Although we believe that volunteers can contribute greatly to the protection of the rights of vulnerable adults, nevertheless, we do not think they can fully replace trained, paid staff. Their contribution is limited by the fact that they may go south in the winter—lucky them—or north in the summer. They get married, have children, change jobs, move their homes, and for other reasons become unavailable. They serve a tremendous purpose in many, many ways; excellent volunteers, but not to take the place of trained staff.

However, if a volunteer program is to be implemented, we strongly recommend that it have provision for paid coordinators, appropriate training, adequate supervision, payment for expenses involved and significant recognition of the volunteer's services. This will help to ensure a high quality of those services.

So our recommendation in this area is that OASW recommends that a volunteer program for rights advice be adequately staffed and that provision be made for appropriate training, adequate supervision, payment of volunteer expenses and a recognition of their services.

The next, number four, is around capacity assessments. As I mentioned at the outset, social workers comprise the second-largest group of capacity assessors in the province, next to psychologists. So it's an important area for us.

Social workers are currently, as I mentioned, the second-largest group. This role for social workers has the full support of the profession's regulatory body, the Ontario College of Certified Social Workers. Hence, we endorse the amendments to this bill, clause 90(e) of the SDA, and authorize the prescribing in regulations of standards for the performance of assessments and the

regulating of fees for such assessments.

In many cases, the potential expense has been an obstacle to appropriate referrals for assessments, particularly for individuals without family or funds. Current policy of the capacity assessment office is that only individuals, and not institutions, can apply for financial assistance to cover the cost of an assessment in cases of hardship.

Therefore, recommendation four from us is: We recommend that institutions and service provider organizations be allowed to apply to the fund which exists in the capacity assessment office on behalf of individuals without family or funds who require assessments.

Further, OASW recommends that assessments be subject to quality assurance reviews to protect those assessed and that a user-friendly range of fees be established.

In terms of number five, powers of attorney for persons without families, I'll simply read our recommendation on that, on page 10: OASW recommends that the PGT change its current policy and permit individuals without family or friends to name the PGT as attorney for personal care.

In terms of number six, removal of the validation process, on page 11: OASW recommends that the government inform the public that the rules for powers of attorney for personal care have changed and, in doing so, encourage the public to review its current powers of attorney in view of those changes, so that they may build in the requirements for a capacity assessment if they so wish.

Number seven, I'll read again generally on page 12 of our submission to you, and it reads, and this of course is in relation to consent to treatment plan: OASW recommends the inclusion of regulations that require the input of all health team members to the preparation of such a treatment plan and the determination of capacity to consent to that plan.

If we look at number eight, the issue of rights advice, emergency department visits—we're getting through them—I will read our eighth recommendation here: OASW recommends that ways be found to sustain the improved sensitivity of health care workers in emergency departments to special needs and rights of patients with borderline capabilities through the use of volunteer rights advisers and educational programs.

Number nine is a particularly important one for social work, so I'm going to read that out more specifically. It involves rights information, finding of incapacity and the review process. The existing law, the Consent to Treatment Act, provided extensive instructions to health practitioners in regard to obtaining informed consent to treatment and informing incapable patients of the right to rights advice and to appeal to the Consent and Capacity Review Board if they objected to a finding of incapacity to consent.

The new act retains the instructions about obtaining informed consent—see sections 9, 10, 11, 12 and 13—and completely removes the requirement for the practitioner to inform the patient of a finding of incapacity and to provide information about their right to a review of the finding.

While the previous act was overly legalistic and



bureaucratic in its approach and the process of informing the patient inhumane, in the view of the social workers, however, the new process, which absolves the practitioner of any requirement to tell the patient in a kind way that someone else will be making decisions on his or her behalf, is equally disrespectful of the rights and the dignity of the individual and places too much decision-making power in the hands of health practitioners.

Therefore, our recommendation nine in this regard states: OASW recommends that there be a requirement for health practitioners to notify patients whom they find incapable of decisions concerning treatment in an informal and kind way and that they will be seeking the assistance of a substitute decider on their behalf. As well, they should inform them that they have the right to have this decision reviewed.

Number 10, evaluators under the Health Care Consent Act, is an important piece for us and it reads as such: Parts III and IV of the Health Care Consent Act which deal with consent to admissions to health care facilities and consent to personal assistance plans authorize a substitute to give consent to both admission and to a personal assistance plan if the person is found by an evaluator to be incapable of giving consent.

**1350**

In the definitions of part I, section 2, an "evaluator" is defined as a health practitioner who is a member of one of a number of colleges, including audiologists, speech-language pathologists, nurses, occupational therapists, physicians and surgeons, physiotherapists and psychologists. The definition does not include social workers, although it does permit other categories of persons to be prescribed by regulation.

In that social workers are highly involved currently in assessing the capacity of individuals who may need decisions to be made on their behalf about admissions to health care facilities and in helping to develop personal assistance plans in such facilities, we believe the legislation should include in the definition of "evaluator" a member of the Ontario College of Certified Social Workers.

Recommendation 10 therefore: The OASW recommends that the definition of "evaluator" in part I, section 2 of the HCCA include a member of the Ontario College of Certified Social Workers.

Finally, our last recommendation here, in relation to the admission to a psychiatric facility of persons 12 to 16 years of age, I would read out here recommendation 11: OASW recommends that subsection 32(2) of the HCCA be reviewed and further clarified to ensure that persons over the age of 12 and less than 16 are not denied the protection of an application to a review board concerning their involuntary admission to a psychiatric facility.

Those are our 11 recommendations. They're summarized in the document we gave you, at the back. So now, in the time remaining, we are open to questions here. I have two experts who can answer most of them.

**The Chair:** We have one minute each.

**Mrs Johns:** I just wanted to talk about your recommendation 11. I wanted to suggest that people between the ages of 12 and 16 would still be able to get review under the Mental Health Act, that their right of review

for involuntary admission to a hospital is still prominent under the Mental Health Act. Really, what we're saying here is that there don't need to be two processes, that the Mental Health Act will allow us to get that review if they need that.

You suggested that professionals needed to be kind about telling people that they were incapable, and so we were really wanting to ask you, did you feel that guidelines from colleges were the best approach to talking to individuals about incapacity or did you feel it needed to be legislated? How did you feel that should be approached?

**Ms Guyatt:** I think it would be great to have some guidelines from the colleges, but I also think there needs to be something in the regulation. Certainly in the current act there is a good deal in the regulation that helps people to decide about incapacity and so on. So I think there should be something there that requires them to actually inform the patient and to give at least some indication of the fact that it's open to review, because how are they going to know about the Consent and Capacity Review Board if somebody doesn't tell them?

**Mrs Caplan:** First of all, I'm very pleased to hear that there is going to be legislation that will regulate the profession of social work. I think that if that happens quickly it will solve the problem, because hopefully then you'll be under the health professions legislation or your own separate legislation which could be referenced in this act as an amendment.

I'm not sure if it could be done by regulation. Could the ministry answer that? For the purpose of evaluation or assessment, they've named very specifically individuals who qualify to do those assessments. Do social workers qualify under the act now or would they require regulatory status in order to do that? We'd appreciate that answer on the record.

The question that I have really relates to recommendation 9. I agree with this and I've been suggesting that we have an amendment to this legislation, and possibly as well in the regulated health professions legislation, that would just clearly state out that there is an obligation for the self-regulatory colleges to develop appropriate guidelines to ensure that patients are told when they are incapable and are given information of their rights. You have no problems with that, believe it's an important amendment to the acts?

**Mr Andreae:** I would say so, yes, definitely.

**Ms Guyatt:** Yes.

**Mrs Caplan:** There should be consistency?

**Mr Andreae:** Yes, definitely so.

**Mr Marchese:** There are a number of questions I would have liked to have touched on, but one of the points that interests me is the Advocacy Act and the Advocacy Commission in particular. The repeal of that has many very concerned. You began by talking about how in your association your concern is advocacy for vulnerable adults. So it's quite in keeping with what the commission would have done. You also raised concern about volunteer programs for rights advisers, and if they should institute such a program, you said they should have appropriate training, adequate supervision, paid coordinators, all the things that the Advocacy Act and the

commission obviously were doing and would have been doing. Do you have a comment on the repeal of the Advocacy Act?

**Ms Guyatt:** Yes, I do have some concern about the loss of protection for vulnerable people. I particularly regret the loss of systemic advocacy because there isn't any suggestion to replace that in any way. I think that anyone who has worked in a big system, whether it's government or an institution, hospital, whatever, knows how necessary it is for there to be some outside way of reviewing problems that are brought to the attention of an objective person who has the right to delve into it. I can give you examples of that if there is time.

Last year when I was going around helping to inform people about this legislation, I frequently heard from people in the institutions, in the settings for the developmentally handicapped, for example, where there had been abuses and where the system did not work for the victim and where the administrators' attempts to remedy this were thwarted by the system.

A good example is where cases were identified of employees who had actually abused patients, where they were dismissed and they grieved and the administrators were forced to take them back into the same positions that they had, where they were in contact with the patients whom they had actually physically or sexually abused. This is not uncommon, and I understand it goes on as well in institutions for the mentally ill.

So the current system does not always work in favour of the victim or the vulnerable person. You saw yesterday with a young man who was here how he had been raped and had no recourse to help. So I think that the systemic advocacy needs to be addressed somewhere, if not in an Advocacy Act.

**The Chair:** Time is up. I thank you very much for your presentation today.

#### ADVOCACY CENTRE FOR THE ELDERLY

**The Chair:** Judith Wahl, representing the Advocacy Centre for the Elderly.

**Ms Judith Wahl:** Actually, I'm going to be joined by my colleague George Monticone, who's also from the advocacy centre.

**The Chair:** You can proceed. You have one half-hour, including all questions.

**Ms Wahl:** My name is Judith Wahl. I'm a lawyer and I'm the executive director of the Advocacy Centre for the Elderly. This is my colleague George Monticone, who's also one of the staff lawyers at the Advocacy Centre for the Elderly.

Now, for those of you who are not familiar with our service, we're a community legal clinic that provides legal services to low-income seniors in the greater Metropolitan Toronto area. We also engage in public legal education programs and law reform activities across the province on behalf of low-income seniors. We're a unique service. In fact, we're the only kind of service of its kind in all of Canada. I think it's a credit to Ontario that we have such a service. With the aging population, elder law is a growing field of legal practice. We've been in operation since 1984.

Our practice is limited to seniors 60 and over. Actual-

ly, probably the average age of our clients is the mid-70s. A third of our practice focuses on client problems related to powers of attorney, elder abuse and competency issues. Based on this experience, from the high volume of cases that we do in this area, the large number of people whom we assist in this area of law, we've developed our response to Bill 19.

**1400**

We see at first hand what happens if the needed protections are not in place to support capable seniors in exercising their own decision-making authority. Unfortunately, whether we like it or not, we still live in a very agist society that often assumes people are not as capable as they are, particularly as they age, and I'm going to give you some examples as I'm talking through this presentation.

We also see first hand what happens if people are not informed as to the decisions others are making for them and what happens if they're not aware of their rights when decision-making authority is inappropriately taken away from them. The result is very distressful to the individual senior and it causes a lot of problems, not only for that person but also for systems. People become very distrustful. In fact, when I read Bill 19, some of the provisions, if some provisions go through on the Health Care Consent Act, I intend to sit down with my doctor and contract with her that she will guarantee that she will tell me if she thinks I'm incapable before she turns to my substitute, because I want to know. I want to have that opportunity. We see this from the seniors. They are very distressed if they're not told in that process.

This also ends up being very costly to services. People end up not cooperating because the distrust occurs. The communication diminishes, not increases, and overall it becomes more difficult for everyone concerned—the seniors, the service providers and the families.

We have a keen interest in the development of this law because of our practice. In the past, historically, we've been participating in all the consultations over the years, with consumers, seniors, other advocates, as well as health care providers, social service workers and the government. You might be aware that I am the chair of the interim advisory committee to the office of the public guardian and trustee on the implementation of the Substitute Decisions Act.

That does not mean that I don't welcome some of the changes in this bill. I think this is all part of a process. Certainly there are things in the existing legislation that warrant changes. However, I'm going to highlight some of the things that we are concerned about that we don't think will be beneficial in this process.

Before I begin with that, I want to give you one example of one of my clients who was caught in a web of not being informed. This woman was in her 90s. She was deaf. She lived in a chronic care hospital. She was very capable. What happened was that she was the subject of a guardianship application. Although the legislation provided—this is prior to this legislation—that she was to be served with notice of the guardianship application, she was not; it was served on the hospital administrator. No one told her that the guardianship application was pending.

The assessment that had been done on her had been



done in a very cursory manner by someone who didn't know that she was deaf. She was very social, so she, during the assessment, sort of nodded yes and no, and of course she failed the assessment, because she didn't hear the questions being asked of her.

She actually found out about the guardianship application from a distant relative. She was very upset at not being informed. She was not incapable.

When we got involved, we assisted her in unravelling this process, but that took a lot of time and money. In the end, a very good result occurred. After she got involved in the process, she willingly did a power of attorney for property to another relative to assist her with her finances. She was greatly offended that somebody had thought she was incapable—in fact, she was quite competent—but there had been an assumption that, because she was old and frail, she was no longer capable. The story ended up with a positive note, but you can see what happens when people are not informed.

We have copies of two bills to make it easier to go through. I'm going to direct you first to the Health Care Consent Act submission.

At the beginning of the Health Care Consent Act, it sets out its stated purposes in section 1. I was quite intrigued by this, because certainly we would support these principles and would hope the legislation reflects these principles. However, in particular, we don't think the legislation that was drafted actually fulfils these principles, particularly the principles in relation to autonomy and communication. If anything, I think the Health Care Consent Act will destroy the communication between people and their health providers.

I guess our major concern with this is the issue of no need to communicate the finding of incapacity and also the loss of the rights advice.

Under the Health Care Consent Act, a health practitioner may find someone incapable of making treatment decisions, and evaluators may find someone incapable of making admission or personal assistance plan decisions, and they're not required to convey that finding to the incapable person. Once the person is found incapable, the substitute decision-maker can be approached for a consent and the treatment can go on. As we've written into the paper, what we have here, I think, is a total failure to communicate.

The fact that there are all kinds of appeal procedures in the act, well, that's real nice, but it's window dressing. If you don't know about your rights of appeal, they aren't going to be acted on. In fact, I would predict that you might as well close down the Consent and Capacity Review Board after Bill 19 is passed because nobody's going to be there because nobody's going to know that it exists.

We think there are two remedies to this. The first is changing the legislation, changing it to require that the health practitioner or the evaluator, where appropriate, must tell the person when a finding of incapacity is made. There were a lot of criticisms about the Consent to Treatment Act. People felt that they had to sort of do a standard kind of format and that was not sensitive. You can work into the legislation a more flexible method of informing the person but the fact of not communicating,

not informing, would be not acceptable. But there are ways of talking to a person. Certainly I've had to face that in my own legal practice with some clients, where I've had to tell them that I can't act for them because they're not capable. I know it's really tough. It's probably one of the toughest things you have to do, but if you can't act, you can't act. If the physician doesn't believe the person's capable in respect to treatment, then they can't take that instruction, but surely part of the professional mandate is to figure out how to tell that person and to retain the trust, to retain the relationship.

Secondly, the requirement for rights advice whenever a person is found incapable in respect to treatment must be restored. If you don't have the rights advice, if you're not telling people about their rights of appeal, as I said, the appeal rights are moot. How do we get the rights advice in if there's no Advocacy Commission to provide the rights advisers? There are alternative means. I think we can be quite creative.

Community legal clinics may be provided with staff to fulfil this function in the jurisdiction in which they operate. You have a system of 72 legal clinics around the province. We are what sometimes is called the cheap and cheerful side of legal aid, because we're a capped budget. Certainly, this is the kind of service that can be incorporated into the services that we provide. Other existing services independent of the health system could also provide this rights advice service. We have duty counsel programs now—I'm not suggesting the duty counsel program be used for this purpose but similar programs could be developed as that type. Also, 1-800 numbers could be used in some areas that are more remote. Where you can't get the body to the person, you can get the phone to the person.

The second way of correcting this problem in the legislation is to wait for a charter challenge. Do you really want to pass legislation that is not charter-proof? In our opinion, this legislation would fail under the charter. It would breach the security of the person. You're going to end up in litigation that is costly, is going to take time. What will be accomplished by that? I think it's a lot easier to change the legislation up front.

Other key issues under the Health Care Consent Act: One of our other concerns is the statement regarding the relationship of the substitute decision-maker to the person, which is no longer required. The Consent to Treatment Act requires that a family member who comes forward as a substitute decision-maker has to make a written statement as to who they are, why they have the authority to make a decision on a person's behalf and the fact that the person would not object to them making the decision. Basically, that statement is a jogging-of-the-memory type of thing. It's to remind people that there might be people in priority to them that should be the substitute decision-maker for treatment for this person. I've had many clients, many calls to our office, where people will phone up, the families will call, they'll start discussing an issue with us and I'll say, "What's your authority to act?" They say, "We have a power of attorney." If you probe further, you find out it's a power of attorney for property, not for personal care, so they don't have the authority that they

think they have.

Having people sign this kind of statement is just a jog to them that there might be somebody in priority to them. It's not taking any power away from the family members. In fact, it's honouring the fact that a person may have done a power of attorney, has chosen somebody other than the person who's sitting in front of the health practitioner. This way, the family member can be respectful of all the players and get the right decision-maker there.

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Another concern we have is the failure to define "crisis" in admission situations. In the emergency provisions under this act, there's a provision where a person may be authorized for placement in a long-term care facility without consent, and it's on the basis of a crisis. I think this is a good provision to include in the legislation. However, when I first read it, I kept on going: "Which crisis are we talking about? Are we talking about crisis related to the individual?" And then that makes sense. But we've had three cases in our office where hospitals have claimed that they are in crisis and for that reason they're forcing the transfer of a senior citizen out of their facility into another facility that's not of their choice. With the long waiting lists, once you get into a long-term-care facility, it's extremely difficult to transfer out into another facility. So once you're in, that's it. So I think it's inappropriate to put on the backs of senior citizens the problems in the health care system.

I'm not saying the hospitals don't have problems with backlogs and people who should be placed in the appropriate level of care. What we're saying is that we have to appreciate that the crisis has to relate to the individual's care and needs and not to an economic problem that's occurring within a facility. Because once the person's moved, they're not going to be able to move to a facility of their own choice, or it's very unlikely they'll be able to move. I think this is very disrespectful to the senior population.

One other comment about the Health Care Consent Act: Health practitioners, evaluators and capacity assessment. This is what appears on page 11 of our brief. The Health Care Consent Act assumes that all health practitioners are able to assess whether a person is capable with respect to treatment decisions within their particular field of expertise. It also assumes that certain persons known as evaluators can assess in respect to admission to long-term care. Our experience with the Consent to Treatment Act and Substitute Decisions Act is in fact it flushed out the fact a lot of health practitioners don't understand their role in assessing capacity. There has been a lot of confusion over capacity assessment, and part of it is the confusion over the law, but they don't understand what they're supposed to do. They haven't received the training. So I think it's fair to have some confusion about this.

We've had questions put to us. We've been told that, "Well, I can't provide treatment to somebody because the person's objecting to treatment." When I would ask the health practitioner, "Well, is the person capable or not?" they go: "Oh, no. All that's important is that they're objecting." Well, that's not what the Consent to Treat-

ment Act says. It says that you have to determine if the person's capable or not. If they're not capable, then there's a certain process. But then you can turn to the substitute decision-maker. You don't have to put that person in jeopardy because you're having a problem in making a decision. What we often saw is that some health practitioners were very reluctant to make decisions because they didn't understand how to do the capacity assessments.

I've spoken all over the province teaching these acts. Many of the sessions we do are to health providers. It's very interesting to see that, once we had some education within the area, people said: "I understand it. I can work with it. I know what I'm doing. I've got a lot of confidence in this." We had a one-day-long session up in Fort Frances that I particularly remember, because one of the surgeons turned to me and he said: "This is nothing. I can work under the CTA because now I understand it." But you have to have that understanding. So we're recommending that there be training for health practitioners, for evaluators, to be able to do their job, particularly for the evaluators. They're not working in assessing capacity in their field of expertise. You're asking audiologists to assess capacity in respect to admission? That's a different kind of capacity.

Just a few comments on the Substitute Decisions Act. We have the same concerns about the lack of rights advice under the Substitute Decisions Act, but something that's of particular concern to the senior population is the witnessing of powers of attorney for property and personal care. This is on page 3 of our SDA brief. The amendment act would permit children to be witnesses to powers of attorney. Now, I'm saying this without any disrespect for families: Unfortunately, there are some people who are going to take advantage of that situation. I think you're opening the door to unnecessary abuse if you're saying a child is going to be a witness. A child is somebody who can profit from the estate of a senior, so why have them as witnesses? You might as well take out all the prohibitions against witnessing for anybody if you're going to go that far, and I don't think that would be reasonable. Just remove the conflict; you avoid the real potential for problems. Again, I don't think there's difficulty in getting witnesses other than the children in those circumstances.

Again, I'm saying this also from our experience of many times. Particularly when people are having hard economic times, they might try to take advantage of the situation to get mom's money. And we don't want that situation to be exacerbated.

Another point is service providers as guardians of property of the person. This is one we have deep concern about, again, based on some of the cases that we've done.

The Substitute Decisions Act would prohibit a person who provides certain services for compensation from acting as guardians of property or of the person. However, the amended act would not only let these people act in that capacity but would also put them in priority to the public guardian and trustee. With all due respect, this doesn't make sense. The public guardian and trustee is a decision-maker; a service provider is a service provider.

Let me give you an example of what you could be



opening the door to, and this is a case that we have worked on. It's in the recent past. We dealt with a care home, so it's a type of boarding home situation in which services are provided for seniors, which was in financial straits. One night they disappeared, in effect, and moved all the people who were in that facility to another facility in which the operator had a monetary interest. Even the personal goods of the people were left behind in their rooms. These were capable people who were moved, without their authority, without their consent, without their permission, but because they were dependent upon the service provider for assistance, that's how much authority the service provider had.

Now that matter is unravelling. What would have happened if a service provider had full authority as guardians of property and the person? Remember that in guardianship applications family members do not need to be served. A guardianship application could go through without people knowing.

The last point I just want to make through the questions is our concern about the activation of the power of attorney for personal care. The way Bill 19 has set it up is that the power of attorney for personal care would be activated in the same way as the financial power of attorney, which is, if I give George my power of attorney for personal care, he thinks I'm incapable, he just can start using it. He doesn't have to tell me that he's using it. Again, we think that this could lead into a lot of problems. What if I'm not incapable? What if he's jumping the gun? It could cause a tremendous amount of distrust between us.

I think it is appropriate that the attorney must inform the person that they're going to use the power of attorney for personal care, and that they believe the person's not capable of making the decisions, and that should be placed within the legislation.

Likewise, we think it should be clear in the legislation that the attorney for personal care should stop acting for the person if they become capable again. So say that I was incapable for a period of time. George started using my power of attorney. I again become capable. He should stop acting, and that should be clear in the legislation. I don't think it's clear now. You're going to cause a lot of confusion if you don't clarify that.

You see our briefs we've given you. The other points we haven't had the time to mention all of them. I'll leave those to you for your reading, and we're open to questions.

**Mrs Caplan:** How much time is there, Mr Chairman?

**The Chair:** Twelve minutes. So that gives us four minutes each.

**Mrs Caplan:** Right. Excellent brief. Thank you very much. Actually, you made a couple of points that haven't been dealt with before. The first one that I think is an interesting one is the one relating to the power of attorney. It was always my assumption that you couldn't use a power of attorney unless you had been declared incompetent for health—personal care reasons, and secondly, that it would cease if your competency was restored. I think that should be clarified if in fact you're right, and I'd ask the ministry to let us know how that works and

whether it needs clarification. That's a good point.

You also raised something that has only been touched on by others that we think is extremely important. That's the issue of training and quality assurance for evaluators and assessors and rights advisers and so on. It's been my view that the Psychiatric Patient Advocate Office, who will be the only ones left with any experience in this field, would be the appropriate ones to undertake and perhaps certify those who could do training. They could do the training and do the certification for anyone that has taken their course that they believe would be a good rights adviser.

Do you think that's a good solution to that?

**Ms Wahl:** Are you talking for rights advice or for capacity assessment?

**Mrs Caplan:** I think rights advice, because that's what they do. As far as capacity assessment, I don't know that there is anything which is consistent across the province. Each of the colleges would have responsibility for ensuring that their members were up to standards, but for rights advice, to have some consistent approach, I thought the PPAO may be the appropriate body to do that.

**Ms Wahl:** Certainly that's one of the avenues. There's no question, because they've had the experience. I think there are other players that also have experience, but I think that's a very good suggestion.

1420

For capacity assessment, I would also bring attention to the capacity assessment office. The whole concept behind that office and why it was developed was to try to develop a common standard. I can remember sitting on the Fram committee years ago, and the original intent was to try to get all the different players who do capacity assessment a better understanding of capacity. The one thing I've learned in the last 12 years working in this area, is that people don't understand capacity assessment and we're in our infancy of understanding it.

**Mrs Caplan:** It will evolve.

**Ms Wahl:** This is part of the evolution. We can learn from that. There is a massive training manual from that office that could be used in training people and to have better understanding.

**Mrs Caplan:** The other concern is that there is no mandate in this legislation for anyone to educate, whether it's the public providers or families. I've always thought that could be a role for the Consent and Capacity Board who are the one independent source, and they give judgements from their experience. I know that they've been doing some education, particularly of providers, and they answer questions, but it seemed to me they could be given a mandate here—

**Ms Wahl:** I think that's one avenue, but they are a tribunal and there are other options. I'll tell you, I can speak for ourselves—

**The Chair:** Excuse me, Ms Wahl, we have to move to the next presenter.

**Mrs Boyd:** You've given us a great deal of material, and I know you've only been able to touch on some of it.

**Ms Wahl:** Our original analysis was 200 pages.

**Mrs Boyd:** I can assure you that we will be very careful about looking at the full analysis.

I must say that in what you said you very succinctly

summarized a lot of the concerns we've already heard around the rights advice issue, and particularly the necessity for someone to understand that they have been deemed to be incapable because that, it seems to me, is the crux of the matter here in terms of getting the whole process started.

There have been some questions raised about the Ulysses contract and the waiver there. We had one delegation yesterday; I expect we will hear more about that. I note that you've got a bit of a critique around how those waivers actually work and whether in fact it does what it's supposed to do. Would you comment on that for us?

**Ms Wahl:** Under the amending act it's a standardized form, and what we're proposed is that people be given the right of choice to choose how much authority they want to give that person. If the whole idea behind powers of attorney for personal care is they are to be personalized, then that option to personalize should be retained; as well, all those persons who already had registered Ulysses agreements be informed of the changes, because with all due respect the transition section changes those documents dramatically. So they need to be informed.

**Mrs Boyd:** To protect them.

**Ms Wahl:** Yes.

**Mr Marchese:** We appreciate your brief very much. I think you have a wealth of experience in working with vulnerable citizens and I hope the members get an opportunity to read the entire submission you made, not just the ones we've heard.

My comment, briefly because we haven't got much time left, is on the Advocacy Act. You talked about rights advisers and said that if they are to be eliminated, hopefully they would do a number of things, 1-800 numbers which they like to do, but legal clinics perhaps is another alternative. As much as some of these alternatives need to be in place in the event they abolish it, as I think they will, I don't think they will be adequate. Part of what the Advocacy Act does through the commission is to provide a mechanism to coordinate all the services, which no one has done or can do, so that if you give some money—which they won't—to some organization to do a little extra, it won't suffice to get to the systemic problems the Advocacy Commission was, in part, also wanting to do.

Do you have a comment on what it means to lose the Advocacy Act and the commission?

**Ms Wahl:** We were very strong supporters of the Advocacy Act on the basis that, from our experience in our work, we saw the need for additional advocacy services, we saw the need for the social advocacy services. I participated in the O'Sullivan inquiry commission. We see it first hand. I agree with you that the other replacement models are only pieces. Having a comprehensive system would go a great deal of the way to assist vulnerable people.

**Mr Tilson:** Brief question, depending: Most lawyers will tell us, of course, that the law requires that notice be given to people if an application is being made or consideration is being made to review their competency. Some doctors, some medical health care providers, will come and say that in some situations that may cause a deterrent

and, furthermore, that they have a professional obligation to provide such notice. This issue is giving some members of the committee some concern and obviously you as well, and that's assuming we have defined who assessors are, their qualifications etc.

If notice is to be given, how should that notice be given so that it won't be hampering the doctors or the medical health care providers so that their concerns won't be alleviated. In other words, do you get a formal notice, a complicated piece of paper? One of the previous people who was speaking just prior to you talked about providing notice in a kindly way. I think it was a social worker group. There are all kinds of ways in which that could be done. Have you philosophized on that?

**Ms Wahl:** I think you start out by talking to the person, quite bluntly, you should tell the person, you talk with them—

**Mr Tilson:** I appreciate that but—

**Ms Wahl:** —and you use your professional judgement in doing that.

**Mr Tilson:** If I could just throw out to you, though, you were suggesting a form of amendment to the legislation.

**Ms Wahl:** Yes.

**Mr Tilson:** You can't say it just like that. What sort of notice—

**Ms Wahl:** I think you can say in the legislation that the health practitioner must inform the person. I think there can be some degree of flexibility on how you do it. I like the piece of paper. I sat through all those debates for years, and believe me, this was an issue that was tossed around and tossed around, "How do you do this effectively?" Pieces of paper are easy and they also perform for everybody; it's something of a comfort. But that doesn't replace talking to people, so it's literally addressing the person, talking with them.

I don't think you have to have a standard script, but I think you have to have the person advising them that they have found them incapable of turning to a substitute. The language they use can be up to them and they can give it on a piece of paper so that it's covered in both directions if people misunderstand. It's basically what's in the Consent to Treatment Act now.

**Mr Parker:** Thank you very much for a very well delivered presentation. I find much to recommend it and much I'd like to talk about. There is one question in particular I'd like to address and that relates to recommendation 9 that I see on page 9 concerning the Substitute Decisions Act.

That is your concern that, as drafted, this bill would not allow the public guardian and trustee to look behind a power of attorney that's presented. He has to take it as given and defer to it and you would rather have the public guardian and trustee have the power to sniff around a little bit if they think something fishy's going on.

I want to make a point and then ask a question. What we have heard loud and clear as a concern about the present legislation is exactly the opposite, that people don't want public bodies to have the power to go rooting around in their personal lives, that they want to have the discretion to put their wishes in a power of attorney and



say: "This is what I want. Go away, leave me alone."

To address your concern, wouldn't it be possible for a person who sees that problem coming down the road to put a provision right in their power of attorney to say, "If it turns out that the public guardian and trustee is concerned about the bona fides of the situation when this document is presented, then they have the authority to go ahead and make inquiries"? In the alternative, doesn't the public guardian and trustee have the authority to apply to a court to object to the application of a power of attorney if they think the circumstances around its exercise are fishy?

**Ms Wahl:** Under the way the legislation is drafted they can't. I'm not saying they go fishing. What I'm saying is, the way I read the legislation, it just says, "If I have a power of attorney and if George is the public guardian and trustee, I give it to him and he has to step out." Can they question the validity of it at all? Is it in proper form? If they have information from a third party, if they've been advised that this was obtained under duress—I can tell you, a high proportion of our practice is dealing with powers of attorney gone wrong, and so that's what we're basing this on. If they have information that would lead them to believe there was something wrong, let them look into it. We're not saying, "Look around." They don't have the time, they're not going to do that.

**Mr Parker:** I'm not suggesting that's what you're suggesting. What I'm suggesting to you is that they still have the power under the proposed bill—

**Ms Wahl:** I don't see where it is.

**Mr Parker:** —to apply to a court if they think the circumstances are inappropriate.

**The Chair:** I'm sorry, Mr Parker, the time is up. I'd like to congratulate you on your report. I wish this committee had an hour to spend at least on it with you, Ms Wahl. It was an excellent analysis of both acts and thank you very much for your presentation.

**Ms Wahl:** Thank you for the opportunity.

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#### ONTARIO HOSPITAL ASSOCIATION

**The Chair:** The next presenter will be the Ontario Hospital Association.

**Mrs Caplan:** While they're coming forward, Mr Chairman, and settling in, Mrs Etta Ginsberg-McEwan, who was here this morning, left a note. Perhaps I could just read it, it'll take a minute, and put it on the record. What she says is, "I didn't have time to make two important points." Could I make those?

**Mr Tilson:** Why don't you copy the note and give it to us?

**Mrs Caplan:** I told her I'd read it in the record if we had two minutes.

**Mr Tilson:** We've got delegations sitting here and we're already over time.

**Mrs Caplan:** All right. I'll wait until there's time. It could have been done if you'd just let me do it.

**The Chair:** We can deal with it at the end of the day, if that's okay.

**Mrs Caplan:** That's fine. We'll do it at the end of the

day.

**The Chair:** Welcome this afternoon. I would ask that you identify yourself for the purpose of Hansard.

**Ms Marion Leslie:** My name is Marion Leslie.

**Ms Carolyn Shushelski:** I'm Carolyn Shushelski from the Ontario Hospital Association.

**The Chair:** We have one half-hour set aside for you. That includes questions and the floor is yours.

**Ms Leslie:** Thank you for the opportunity to appear today before the committee as it considers Bill 19, the Health Care Consent Act. My name is Marion Leslie. I'm the president and chief executive officer of Providence Centre, a chronic hospital and rehabilitation hospital in Scarborough, and I'm also chair of the Ontario Hospital Association task force on consent, substitute decisions and advocacy. I'm joined by Carolyn Shushelski, legal counsel to the OHA.

This is actually the third time over the last four years that the OHA has appeared before this committee to present its views on legislation introduced for the purpose of protecting the rights of vulnerable people in health care facilities.

The legislative package on advocacy and consent, originally introduced in 1992, was an extremely complex one with four bills sponsored by three different ministries. Although supportive of its underlying principles, in our view, it introduced many procedures which ultimately are unworkable and established unnecessarily complex and adversarial procedures involving patients and their families, providers, the government and other parties.

In April 1995, the legislation was proclaimed. Seven months later, Bill 19 was introduced. If passed, it will repeal the Advocacy Act, replace the Consent to Treatment Act with the Health Care Consent Act and amend the Substitute Decisions Act and other related statutes.

In anticipation of the challenges of applying the new legislation in a health care setting, the OHA established a task force to develop guidelines to assist hospitals and health practitioners in the development and implementation of policies and procedures for their institutions in order to meet the requirements of the legislation. As I indicated in my introduction, I am the chair of this task force. The membership of the task force includes representatives of our member hospitals, and that includes trustees, administrators, physicians, nurses and staff of health records departments. It also includes membership from the Ad Hoc Coalition on Consent to Treatment, Substitute Decisions and Advocacy, and the Ministry of Health.

We have included a detailed list of our membership in our document. After almost a year and a half of work, the task force completed a reference manual on the legislation for hospitals which was distributed to our members in March 1995. I have a copy of the manual here to give you some idea of the extent of the complexity that was required in interpreting and helping our member institutions develop their own policies and procedures.

We also organized a number of educational sessions for our member hospitals. In addition, individual hospitals established their own committees to study the legislation and to develop policies and procedures to respond to the legislative requirements. Hospitals also had their educa-

tional sessions. Due to the complexity of the legislation, it was an enormously time-consuming exercise. The costs incurred by the OHA and the hospitals to develop the manual and the policies and procedures and to organize the sessions was indeed significant.

It was during the process of attempting to translate the legislation—even after it had undergone extensive amendment in the legislative process—into practical administrative and clinical guidelines and procedures that our original concerns about the legislation were heightened and we became convinced that certain aspects of the legislation simply would not work in practice and that there were components of the legislation which needed to be seriously reconsidered.

Given the somewhat tortuous history of patient rights legislation in this province, I am sure that you can appreciate we are approaching this new bill with some caution and concern. However, having now conducted an examination of the legislation, we are here today to advise the committee that we believe that Bill 19 does appear to address many of the concerns which we had identified in the previous legislative package.

We would now like to offer for your consideration our commentary on what we believe to be key sections of Bill 19.

OHA supports the new definition of “treatment” and the exclusions to that definition. The addition of clause (g) that deals with non-harmful treatments is particularly helpful.

Bill 19 provides definitions for “course of treatment” and “plan of treatment.” The members of our task force spent a great deal of time researching and developing definitions for a plan of treatment and a course of treatment and we are pleased to see that the definitions in the new act reflect the definitions which were developed by the Ontario Hospital Association task force.

Bill 19 removes requirements that rights advice or notice respecting rights advice be provided to a person who is found incapable by a health practitioner with respect to a treatment. This removes one barrier to timely care, though it raises other concerns.

OHA believes that the appropriate role of the health practitioner is to provide care and treatment to the patient, which includes obtaining the appropriate informed consent.

Under Bill 19, a health practitioner is not prohibited from administering treatment after confirmation of a finding of incapacity by the Consent and Capacity Review Board, and the seven-day period during which the board’s decision can be appealed, unless one of the parties indicates to the health practitioner that he or she intends to appeal.

OHA supports this change as it will enable, in most circumstances, the required care to be delivered without delay. However, where an application is made to the board, treatment delays can still occur between the time a patient is found incapable and the time of that hearing.

This bill clarifies the test for informed consent, and we support that change. We believe that the legislation sets out the test for informed consent in a manner which reflects that which is outlined in our reference manual, and clarifies those aspects of the test that were somewhat

cumbersome respecting what the health care practitioner must disclose to the patient about the material risks and effects involving alternative courses of action.

Under Bill 19, a health practitioner is entitled to presume that consent to a treatment includes consent to a variation or adjustment in the treatment or to a continuation of the treatment in a different setting if the risks and benefits are not significantly different as a result of the variation, adjustment or change in setting.

This change addresses two practical problems that we identified in the course of our review with respect to the existing act and the preparation of guidelines. In the first instance a physician, for example, may obtain consent for a particular medication and writes an order for the administration of the medication. It may be necessary to make minor adjustments to the dosage or frequency in the administration of the medication. The amendment will permit the required medication changes to be made in a timely manner. In the second instance, where a patient is transferred from one facility to another, a treatment started in one facility can be continued without interruption upon the patient’s transfer to the other facility.

We support this change because it allows for these minor variations in treatment. We believe it is a more reasonable and practical approach to the delivery and management of the care of a patient.

The act stipulates that if a plan of treatment is developed for one person, one health practitioner may, on behalf of all the health practitioners involved in the plan, propose the plan to the person, determine the person’s capacity with respect to the plan and ensure that consent is obtained.

We believe that it is reasonable and practical for the overall management of a patient’s care that one health practitioner obtain consent to the whole plan. We also believe that for a particular treatment, only a health practitioner who has the knowledge to impart the appropriate information about the treatment and to answer the patient’s questions about the treatment should be the person who obtains the informed consent for a particular treatment.

We would also expect that individual practitioners will continue, as part of their own standards of practice, to obtain consent for a particular treatment if they believe they should do so.

The new act will continue to provide a list of possible substitute decision-makers and will rank the persons on the list. OHA supports this, as access to a list of substitute decision-makers is necessary when a person who requires care is incapable and consent must be obtained prior to treatment being administered. We also support the public guardian and trustee continuing to be the decision-maker of last resort if there is no one else on the list to make the decision or if two or more persons of equal rank disagree.

In the preparation of the OHA reference manual, task force members discussed the need to provide caregivers with some assistance as to who is to be considered a relative. Therefore we are pleased that the new act clarifies that relatives are persons related by blood, marriage or adoption.



While supportive of all the other changes to this section of the act, we would like to point out the potential for conflict which may arise, given the change which now ranks parents and children equally as substitute deciders.

Under Bill 19, formal family member statements will no longer be required. As well, health care practitioners will be able to rely on assertions made voluntarily by anyone who gives or refuses consent to a treatment on an incapable person's behalf. We are supportive of both these items.

Bill 19 permits emergency treatment without the consent of an incapable person if the communication required in order for that person to give or refuse consent cannot take place because of a language barrier or because the person has a disability that prevents communication from taking place. We support this because of the inherent difficulties hospitals face in obtaining comprehensive and timely interpreter service in all instances. However, we want to emphasize that we support this provision being a limited authority only to act in an emergency.

Under Bill 19 the health practitioner may treat in an emergency despite the refusal of a substitute decision-maker to consent, even if the substitute decision-maker is a guardian of the person, an attorney for personal care or a board-appointed representative, where that person is not acting in accordance with the principles of the act. OHA strongly supports this change because we believe a patient is entitled to receive appropriate and timely treatment and that a substitute decision-maker, regardless of the category, should act in accordance with the principles of the act. If they do not, then the health practitioner should be able to administer the treatment.

Given our strong belief that a patient is entitled to receive treatment in an appropriate and timely manner, we support the provision in the bill which permits the health practitioner to apply to the board if he or she is of the opinion that a substitute decider who gave or refused consent to a treatment on an incapable person's behalf did not comply with the decision-making principles set out in the act.

Bill 19 provides a model for obtaining consent on behalf of incapable persons for admission to health care facilities. Under the existing act, admission is tied to treatment, and this has posed problems when individuals do not require specific treatment as defined by the Consent to Treatment Act, but do require admission to a long-term-care facility. The ability to access the hierarchy of substitute deciders is useful for purposes of admission, and we support the proposed model in this bill.

Some patients who are incapable may require assistance with certain activities of daily living. These activities may include hygiene, dressing, ambulation, washing, grooming, elimination, positioning and other routine activities of daily living.

Under part IV of Bill 19, a framework is introduced for personal service assistance plans. We believe that the intent of part IV is that where a person who is incapable requires assistance, or the provision of assistance with these activities, the hierarchy of substitute deciders may be accessed for consent.

If this is the intent, then we support part IV, but we

would recommend that the term "activities of daily living" be substituted for the term "personal assistance services"; "activities of daily living" is the term commonly used in practice. In this regard, we understand that the ad hoc coalition will be making a submission that will suggest a definition for "activities of daily living" as follows: "an activity that the person performs routinely and may include activities such as hygiene, dressing, ambulation, washing, grooming, elimination and positioning or other routine activities of daily living." We would support this definition.

Part IV of the bill as presently drafted applies only to certain care facilities. We would suggest that it should apply to hospitals and other health care facilities as well. This is consistent with our previous position that the approach to care and treatment of a patient should not be dependent upon a location but should be related to the treatment that is being proposed.

In conclusion, it is our view that Bill 19 represents a package of reforms, refinements and adjustments to consent to treatment and substitute decision-making that is fair and balanced. Bill 19 is a workable resolution to the practical difficulties that currently exist in the legislation. It requires the health practitioner to obtain, from a patient or a substitute decision-maker on behalf of an incapable patient, an informed consent to treatment prior to the treatment being administered while ensuring that timely and appropriate treatment can be administered in emergency situations.

We also believe that the government needs to give consideration to ensuring that information is made available to the public about the new legislation upon its proclamation.

**Mrs Boyd:** Thank you very much for a very thorough job in terms of dealing with concerns that I know you had raised before, and that's very helpful.

On the section on page 5 where you're talking about personal assistance plans and wanting that language changed to "activities of daily living," we've had that suggestion from a number of other people and in that regard had expressed to us a very strong concern around the issue of both nutrition and hydration in terms of where they fit in, whether they are a treatment or whether they are part of those activities of daily living. The concern was raised that there is a practice that still exists in many cases where food and water are withheld.

I wanted to find out from you whether you consider nutrition and hydration part of the activities of daily living or whether you consider them as part of treatment, and whether you share the concern which was brought to us by Father Thomas Lynch from the Roman Catholic Archdiocese of Toronto as that being a possible problem, in terms of the explicitness of what can be expected in terms of care, and whether or not it is appropriate for those things to be withheld without express permission.

**Ms Leslie:** Maybe I could just speak personally about my institution and then I'll ask Carolyn to respond more generally. We have very explicit guidelines as to how we handle those situations. They are discussed with the client or the client's family, as the case may be. That's something we monitor regularly and indeed is endorsed by our board of directors. So they're very explicit guidelines that



we have to handle that type of instance.

**Ms Shushelski:** We often talk about, where does nutrition fall in this scheme? I think that it can get somewhat complex in the acute care facility. It seems to fall under treatment in one respect because in a hospital one even requires an order basically even before you can order the diet, and the physician has to at least assess the patient to determine what the problem is because it would be inappropriate otherwise.

On the one hand in the hospital you end up with a situation where you actually have an order written on the chart as to what the diet of the individual is, even if it's a regular diet. There has to be some kind of indication to the members of the team about what this patient's needs are. So to that extent I guess one could argue that if you are making an order for that, that must then in some way be connected to treatment.

On the other hand, outside of that restriction, if you will, you ask a person what he wishes to eat and you provide it within what's available that you can give him. But certainly no one would suggest that it should be withheld from them.

**Mrs Boyd:** But we all know that in terminal cases, and certainly where communication has ceased, we have to agree that there has been a practice at some point in each of those cases where food no longer may be offered. What Father Lynch was talking about was if it is not clear whether that's part of treatment and therefore a substitute decision-maker is asked to approve that or not approve that, or whether it's somehow just left out of this picture and the substitute decision-maker never gets a chance to participate.

I know at your facility it's very much part of the plan and I would think it might be at some. But his contention, having worked in many different areas, was that that is not necessarily true and that one of the problems for incapable patients often is that decision-making around nutrition and hydration seems to get lost in the shuffle.

**The Chair:** Thank you, Mrs Boyd. Your time is up. Mrs Johns.

1450

**Mrs Johns:** I just wanted to ask you a question on your section called "Substitute Deciders." When we were doing reading to get ready for this, we read a lot about the previous act and the controversy that surrounded the hierarchy of who could decide and that it was too long and too onerous. So in effect we grouped people together, and being in the middle generation I can understand how my parents could make a decision for me, or my adult child. So parents and children, for a person like me, were put on the same level—ranking, let's say.

You're suggesting that may not be appropriate. Can you comment on the problems with the old act versus what we've done, how you would change it and what you would like to see?

**Ms Shushelski:** First of all, just to make it clear, we do like the ranking. If we've given the impression that we don't, then just to make it very clear, we do think it's appropriate to have a ranking. It's very useful. When it comes time to find a substitute decider, it avoids a lot of conflicts.

I think the only part we were trying to say here that

we were just a bit taken aback by was the ranking of parents and children on the same line, basically—not a rank, but they actually are on the same line. In our discussions with our task force we certainly had many discussions about who is a relative, whether that's blood or not blood-related, but I don't remember us ever having a discussion about potential conflicts between parents and children. I think that in the previous ranking, the parent or child was one above the other. I can't remember specifically, but there was a clear line that you went first to either the child or the parent and then you went to whichever was the other person. What's changed here, I think, is that now we've grouped two people together, parents and children, and if there's, let's say, one parent and one child—and you say you're the middle child.

**Mrs Johns:** No. I could be the adult and I could have adult children and I could have parents still alive, in the 40-50 age group, let's say. So my parents are still alive. They could choose for me or my adult children could be there. They could be 22 or 23 with my age, and so which one of them should make the choice for me?

**Interjection:** It is a problem.

**Ms Shushelski:** It's a problem, but I guess what we're concerned about is that we would hate to see arguments develop between a parent and child over who's going to make a decision for that person, and because of that argument it ends up in the public guardian and trustee's hands and neither relative ends up making the decision for that person. So in fact you've defeated your whole purpose and somebody completely outside the family ends up making that decision. I can see how between a parent and a child who both care very much about that person—

**Mrs Johns:** That's right.

**Ms Shushelski:** —you can certainly get into many arguments. I don't say we've got the answer; it's just something that we've identified.

**Mr Ramsay:** I want to thank you for your presentation. I wanted to just ask you this. When we talk about the one practitioner to propose the plan, that now the act would allow that if there's a whole plan of treatment, only one practitioner can propose the plan or needs to propose the plan and determine the person's capacity with respect to the plan and ensure that the consent is obtained by the plan, I thought your comment was interesting that you also expect that individual practitioners will continue, as part of their own standards of practice, to obtain consent for a particular treatment if they believe they should do so.

Is that a custom that developed since the last act because people wanted to make sure they were protected, and do you think this custom is going to change now that this act only requires, say, the head of the plan or one representative of the multidisciplinary team to obtain their consent? Do you think that just will go by the wayside or do you think each of the colleges will keep that as a standard and require each practitioner to obtain consent?

**Ms Leslie:** I think that represents current practice, that there will be a plan agreed to and one person can sign off on the consent, but that each individual practitioner, if he or she feels it appropriate, will indeed get the consent for their particular treatment, and so I think that reflects



current practice.

**Mr Grandmaître:** The group that appeared before us, Judith Wahl of the Advocacy Centre for the Elderly, was very concerned about the communications about this bill once it's in force. I see that the OHA, if I'm not mistaken, established a task force to develop guidelines to assist hospitals and health practitioners in the development of the implementation of policies and procedures of their institutions, and so on and so forth. Did your task force go as far as educating health practitioners how to deal with—their recommendation reads, “We recommend that all health practitioners should be trained to do capacity assessment in respect to treatment decisions.” Did your task force go that far?

**Ms Leslie:** No. We see it as our responsibility to have our member hospitals, and the member hospitals have a responsibility to be sure their own staff, are aware of the legislation, so understanding the legislation and their responsibilities around it. But not with respect to training assessors.

**Mr Grandmaître:** Do you think that all practitioners should be trained to do capacity assessment?

**Ms Shushelski:** Probably not. I think what it really comes down to is for what purposes the practitioner is carrying out the capacity assessment.

**Mr Grandmaître:** They claim that a lot of practitioners didn't know what it was, the responsibilities or—

**Ms Shushelski:** I think, in fairness, what's happened over the last several years, and it really does go back certainly into the 1980s as far as I can recall, is there's been a lot of discussion and there's been a process. It's been a development. The whole issue of capacity has been moving along and evolving. When the consent act and the Substitute Decisions Act became law last April, there was a lot of education required and there was suddenly this notion that if you're the person who's actually going to propose the treatment, then you're the person who ought to be doing the capacity assessment, and it sounds logical and reasonable.

**Mr Grandmaître:** Are they trained for it?

**Ms Shushelski:** The difficulty is, I'm not so sure that—well, I think everyone before these acts came into being probably did it on a level where they weren't really saying, “Here are the sections on how to determine capacity, and I have to ensure that each one is followed.” It was the first time we ever really saw anything in writing as to how to actually carry out a capacity assessment.

So I think it's very important that you do think about who is the person who's proposing the treatment and is it relevant or appropriate that if that person is proposing the treatment, they should, if they're going to be talking about the risks, benefits and side effects, also be able to ensure that the person they're talking to understands what they're saying? Because if you're not imparting the right information and you yourself ensuring that that information's coming back that the person understands it, then it becomes a bit difficult.

Should everybody be doing capacity assessments? Maybe not. But certainly if they're not, they have to ensure whoever is doing that capacity assessment is going to be able to appreciate and understand the information

that has to be passed over.

**The Chair:** Thank you very much for your presentation.

1500

## ONTARIO PSYCHOLOGICAL ASSOCIATION

**The Chair:** Our next presenter will be the Ontario Psychological Association, Dr Ruth Berman and Dr Hamovitch.

**Dr Gregory Hamovitch:** Mr Chairman and members of the committee, I'm Dr Gregory Hamovitch, president of the Ontario Psychological Association, and with me is Dr Ruth Berman, our executive director.

The Ontario Psychological Association is a voluntary organization which since 1947 has represented the profession of psychology in Ontario. Our membership of approximately 1,400 includes clinical and academic psychologists, psychological associates, psychometrists and graduate students in psychology. Psychologists hold doctoral degrees and as service providers have been independently regulated under statute in Ontario for over 35 years. Currently, we are regulated by the College of Psychologists of Ontario under the Regulated Health Professions Act.

We are pleased to be able to be here today to express our support for Bill 19. While our comments today will focus specifically on a specific amendment to the Substitute Decisions Act, we wish to state at the outset that we believe that Bill 19, with its introduction of a new Health Care Consent Act and its amendments to the Substitute Decisions Act, will better achieve the goals of simplifying laws respecting consent and substitute decision-making, reduce delays in treatment and restore the appropriate balance in health care decision-making.

We would now like to direct our comments to the particular issue that has brought us before you today. The Ontario Psychological Association had been particularly concerned and vocal about the last-minute changes introduced to the current Substitute Decisions Act, 1992, and Consent to Treatment Act, 1992, prohibiting parents or guardians from consenting to the use of faradic stimulation on behalf of individuals unable to consent for themselves. This amendment was introduced in the absence of any consultation with the appropriate health care professional associations or their regulatory bodies. Response-contingent shock therapy, including faradic stimulation, is based upon a psychological model rooted in behavioural research and theory. In spite of this, neither the Ontario Psychological Association nor the College of Psychologists of Ontario, our regulatory body, was consulted in any way prior to the changes in this act.

In having been excluded from this process, the very groups with scientific and clinical expertise in the treatment of self-injurious behaviour, and the group with a broad knowledge and research base in the area of aversive conditioning, were unable to provide valuable input that might have prevented that unfortunate decision in the first place. At the same time, the government of the day appeared to have responded solely to pressure from a small number of opponents who, however well-intentioned, seemed to have been misinformed about the

use of faradic stimulation.

We are therefore very pleased to note that the present government has recognized the injustice inherent in a prohibition against faradic stimulation based on substitute consent and fully support its decision to reinstate the rights of family members or guardians to consent to its use as a treatment when necessary.

We recognize that the idea of utilizing shock as a form of treatment may raise some emotional reactions and that opponents to the removal of the prohibition to consent to aversive conditioning as treatment will exploit this emotionality. You therefore must remember that this form of treatment is used only in very extreme cases of self-injurious behaviour. One needs only to hear the story of Brian Singer to understand what we are talking about. I understand that some of you will already be familiar with this story and have heard some of these reports, but it none the less bears repeating, because what we are talking about are very, very small numbers of individuals, and Brian's example represents one but is similar to others.

He is a 27-year-old developmentally disabled young man with a 20-year history of self-injurious behaviour. He has been tested and classified as profoundly disabled and functions at the level of a two-year-old with no verbal skills. He also demonstrates autistic behaviours. He was admitted to Southwestern Regional Centre on October 8, 1986. When Brian arrived at Southwestern, he had been wearing a straitjacket, as this was the only means, however inadequate, of keeping him from beating himself. He was wearing a football helmet to prevent him from creating infections in his cauliflower ears by pounding them with his knees. He arrived at Southwestern with a cracked bone in his arm, despite a straitjacket, a helmet and heavy doses of medication. His fingers were also becoming atrophied due to misuse.

With contingent faradic stimulation, he had a dramatic improvement from inflicting several hundred blows to the head per day in 1986 to the point that in 1993 he required only a total of five contingent shocks for the entire year. From 1990 to 1993 there were several months when due to an infection or stress he would require one or two shocks and then they were not required for months at a time.

To give you some insight into the efforts that were made to come up with alternative treatment solutions, I will give you a brief account as follows.

Brian had been on many courses of medication with trials recommended by Dr Hinton, a paediatric neurologist; Dr Goldberg, consultant psychiatrist of University of Western Ontario, and other physicians. He had the benefit of consultations by numerous physicians, including major advocates for other approaches. A full spectrum of new technologies had been tried in addition to new or non-tranquilizing medications. In addition to these, a whole gamut of physical restraint techniques were used such as a four-point bed restraint, manual restraint, wrist cuffs, the latter having been used for several months on a 24-hour basis with the exclusion of eating and bathing periods.

The case of Brian Singer illustrates that aversive shock

treatment is used only in exceptional circumstances and only when all other approaches have failed. Our opponents may argue that the mere fact that it is permitted may lead to its misuse. However, you should be aware that prior to its prohibition under the current legislation at any given time a maximum of only five individuals in the entire province of Ontario were receiving this treatment. Each of these individuals, like Brian, was severely self-injurious and had failed to respond to all other alternative treatments. In all cases, these were administered by regulated psychologists. I have not included this in the brief, but it's very important to note that these treatments were administered by regulated health professionals who are governed under the act and were entirely accountable for their actions by virtue of being regulated health professionals.

Furthermore, the proposed amendments guarantee additional safeguards in that the guardian is prohibited from using or giving consent to the use of shock unless such consent is given in accordance with the proposed Health Care Consent Act. In addition to legislative safeguards, there is another layer of institutional requirements that must be met and which further protect the individual who is unable to consent on their own behalf.

Currently, faradic shock is available only at Southwestern Regional Centre. At the centre, approval and monitoring of the use of faradic stimulation involves reviews by at least four separate groups: the unit resource teams, the facility level behavioural standards review committee, the professional advisory committee, the external review committee, and ministry accountability. Pursuant to the latter, the clinical director is required to submit monthly reports on all faradic stimulation cases to the operational coordination branch of the Ministry of Community and Social Services.

Further to this, any psychologist who would provide such service is regulated in the province of Ontario and governed by the Regulated Health Professions Act.

Faradic stimulation involves the application of minute electrical stimuli to the fatty tissue of the leg or arm of a person exhibiting high-risk behaviour. The stimulation units use less current than a heart pacemaker and produce a sensation ranging from a brief skin pinch to a deep muscle vibration. The side effects, if any, are minuscule in comparison to the potential side effects of the behaviour-inhibiting drugs that are often used but may nevertheless still fail to reduce the self-destructive behaviour in severe cases.

Psychological research has demonstrated that treatment in the form of aversive shock therapy may be the most effective, indeed the only effective—and this bears worth repeating: To this point in time, this form of aversive shock therapy is in fact the only effective method demonstrated in reducing self-injurious behaviour in intractable cases. This evidence has been supported by no less a leading authority than the United States National Institutes of Health. There are, for those who wish, available from us briefs from various organizations within the American Psychological Association supporting this as well.

If severe injury to or the death of an incapable individ-



ual can be prevented with a noxious, but not harmful, shock to the arm or leg then the law should permit guardians to provide consent for its use.

At issue here is the right to effective, individualized treatment of choice. The existing legislation flies in the face of this principle. It says, if you can ask for it yourself you can get it, but if you are not capable of asking for it, well, too bad. The current prohibition discriminates against people with developmental disabilities who need treatment desperately but can't consent to it. It denies the same rights to individualized treatment that we would grant somebody else. It is ironic that those individuals who have special needs, including protection against their own self-destruction, are not allowed to have them simply because they can't express their wish or give their consent. The current legislation effectively prohibits use of a technique which is already virtually never used, thus seeking to protect people with developmental disabilities from a non-existent threat to their wellbeing while depriving a handful of people from receiving the only treatment that has documented benefit in improving their personal wellbeing and ensuring their physical safety.

The standards of practice and codes of ethics of psychology require us to act to protect our clients from harm. While we appreciate that this may not have been the intent, failure to pass the proposed amendment to remove the prohibition against consent will result in unquestionable harm to the affected individuals and their families.

Thank you for attention. Once again, we wish to congratulate the government for its courage and wisdom in proposing these amendments and we look forward to their enactment in law.

1510

**The Chair:** Thank you, Dr Hamovitch. We have approximately five minutes per caucus, and Mr Tilson and Mrs Johns wish to make representations for the government.

**Mr Tilson:** I don't know if you knew that or not, but Mrs Singer appeared yesterday and gave us a very effective presentation and a video on this issue. It certainly had an effect on all of us and we've had subsequent presentations who—obviously there's a debate in the health care business. Some say we shouldn't have it at all, some say that it should only be granted with particular court orders every so many months, three months, and of course you are quite aware what position our government is taking.

Mrs Singer made it quite clear to us that the treatment that was provided to her son was done on much consultation with the medical people who assisted with it. It has been quite clear that the treatment is regulated by health practitioners who are accountable through their clinical practice and through their professional colleges.

My question is, with this controversy, is that enough? Will that satisfy the public?

**Dr Hamovitch:** I can answer that initially. I think if the public is appropriately informed about how the colleges regulate and what are the systems through which people can call into question their accountability, then that will be sufficient. I think like anything that involves some change, there is a need for public education. I am

convinced that with appropriate public education, the public would be satisfied.

**Mr Tilson:** Just one following question: Why this and not others? One could ask the question, why not treat other treatments the same way? In other words, how far does one go? Obviously I support it because that's the position of our government.

**Dr Hamovitch:** There's a simple answer, which is, you have to look at each treatment on its own merit, you have to look at the appropriate research, you have to look at all other alternatives. That's been done in this case. I would suggest that the same kind of thoroughness be applied to any kind of treatment being considered. The answer is not, "Why not for any other treatment?" the answer is, "Well, yes, consider any other treatment with the same thoroughness with which this has been considered."

**Mrs Johns:** I understand that psychologists are basically the only people who are proposing this treatment and I'd like to know what kind of standards, guidelines, current reviews you have on people like Brian to make sure that this treatment is effective and is still the proper treatment.

The other thing—I was trying to get the quotes out of Hansard, but I don't think they're far enough out—I believe someone suggested yesterday that we would then see faradic stimulation in many of our Comsoc facilities throughout Ontario and that it would have increased use. I'd like you to comment on that also, please.

**Dr Hamovitch:** I would ask them why they would suspect that, given that this prohibition has been in place for only a few years. People could have done so for many years preceding and didn't. I have no reason to believe that there would all of a sudden be a whirlwind of activity in an area in which historically there has been no such whirlwind. So that argument doesn't—I'm not sure where it comes from. I assume it's based in ignorance of what existed prior to this law. That would be my answer to that question.

In terms of the former, I think the protection is in respect to the standards of practice for psychological providers. We have very specific and strict regulations and guidelines with respect to our practice that dictate that we must protect our patients from harm in every possible way. That in fact is what is being done by use of this particular treatment modality. That is what protects all our patients, all our clients.

**Mrs Caplan:** Yesterday, when Mrs Singer was presenting, I mentioned that I had met with her and I was very sympathetic about the fact that her only recourse was to the minister for an exemption to the law. I felt that an absolute ban was too restrictive.

The Regulated Health Professions Act deals with the notion of risk of harm, and professionals are given our trust. However, when there is such a controversial therapy, if you want, or treatment—and the reason it's controversial is that not everyone agrees it's a treatment. We heard presentations before this committee that suggested a contrary view.

But I think the issue is broader than just faradic therapy. It has to do with aversion therapies in general and the techniques that are used which the public has

concern about. We've seen documentaries on TV recently suggesting perhaps punishment techniques, that the public would want closer scrutiny.

So the word I would use and the concern I have expressed as it relates to the electroshock therapy called faradic stimulation is, does this amendment, which removes the absolute ban, provide us with sufficient accountability. No one has suggested—certainly, I have not—the potential for widespread abuse or use, but what I am concerned about is that while the facility that it's available in through Comsoc has strict procedures and there is scrutiny and accountability, I would be more comfortable to ensure that there was not any expansion of the use outside of a Comsoc facility; for example, since it wouldn't be illegal to do it any more, to have written in the law a requirement for the guardian or the substitute decision-maker, or the person who would be consenting on behalf of the incapable person, to get approval from the consent board as an accountability check. As I say, there could even be an exemption from that for a Comsoc facility, where you know that you have the standards and the safeguards and the accountability in place. But I'm concerned that if you remove an outright ban, what's to stop a psychologist, or someone who's not a psychologist, from offering this in an unregulated environment?

**Dr Hamovitch:** Firstly, one could argue that, I suppose, a control on it is not allowing anyone to do it but simply allowing those with expertise in psychological theory and practice, that being psychologists, to be the ones who could bring about this treatment.

**Mrs Caplan:** It's not a licensed act.

**Dr Hamovitch:** If that is one restriction you might consider, then you might want to consider whether or not it should be a licensed act, which I understand is not what we are here to do today, but certainly that's something which might come under consideration.

I would not say that, on the surface of it, having had about 30 seconds to think about it, I would be against your proposal either but, again, I would say that what you would want is a board that was at the very least composed of people like psychologists who had some expertise in this area. I think it is important that when you talk about boards and people making decisions, the people making those decisions are people with expertise in the research and in the practice, and not others who might not really understand the implications of the—

**Mrs Caplan:** I agree, because that is the essence of accountability. You can't hold someone accountable if you don't understand what it is they're doing.

If you'd like to think about that for more than 30 seconds and perhaps suggest an amendment that you think would be appropriate, I'd be interested in seeing that from you. And the idea and the notion of this being a licensed act as an option is something else.

My concern—and I'll be really clear about this—I believe that if it is appropriate treatment and deemed appropriate, with all the checks and balances, for those very few individuals, there should be access. I think that access should be tightly controlled because of the controversial nature of the procedure. But having said that, I'm concerned that this legislation removes the ban and eliminates the potential for abuse outside of Comsoc

facilities.

**Dr Ruth Berman:** If I could just add—and I appreciate your asking this question—I can't see how removing the prohibition could potentially result in those problems. Reference was made to the Brian Singer case, and if you know his history, we're talking about this treatment having been utilized in the absence of the prohibition. We're talking about treatment that was initiated after many, many years of everything else being tried. I think the fact that the ban is removed is not likely to result in parents consenting to this without this being in fact a last-resort treatment, with everything else having been considered. This is not an easy decision for a parent or a guardian to make.

1520

**Mrs Caplan:** I understand and I wish I had the confidence—

**The Vice-Chair:** Ms Caplan, we're going to have to move on now. We're going to move to five minutes for the third party.

**Mrs Boyd:** I'm very surprised that for the association to come in front of us this is the only issue you had to raise with a very important bill. But given that it is, I take great exception to the suggestion that the decision of the previous government was made on the basis of a very small number of people who objected. In fact, there had been very great questions asked, and asked in the Legislature of the province of Ontario over many years, about the use of this procedure. There were questions asked among treatment professionals working in facilities in other parts of the province also run by the Ministry of Community and Social Services as to the appropriateness of it.

When I was Minister of Community and Social Services, I visited those facilities to see what they did with similar kinds of cases and how they handled self-injurious behaviour and exactly what went on, and heard at first hand from them their discomfort around this, seeing it not as a treatment but as an aversive behaviour modification technique similar to many others that we've heard about in many parts of the world which have similarly been felt to be inappropriate.

The then Deputy Minister of Community and Social Services went and spent some days at Cedar Springs, in the unit, looking at what went on before any decision was made. We had strong representations from survivors of the various facilities, community living associations. There is on record a very strong recommendation by the community living association of Ontario that this be a banned practice. So I think your characterization of this as a last-minute, ill-thought-out, unsubstantiated decision is, quite frankly, offensive.

It is very clear in the discussions we had that those who are offering that treatment believe it should be more widely used and resent the kinds of constrictions and restrictions the ministry had put on that treatment. The facility is much larger than housing the number of people. When the decision was made to stop that treatment, it was in fact found that of the six people who were receiving it, only two had benefited from it in the first place.

So there are many clinical questions about the effec-



tiveness of this particular treatment. The two issues of whether it's a treatment or whether it is an aversive behaviour modification technique—you can get as many experts on either side to argue that. That was why the situation was there.

You claim that you see no reason why it would expand. There have been instances elsewhere where there have been requests to use that in different facilities, and that has not been allowed by the ministry.

It is certainly a very effective way of changing behaviour, but whether it is an appropriate way is something else. We've had many discussions in this country about treatments that were thought to be perfectly okay. We think of the drug experiments in Montreal, for example; we think of some of the other experiments around aversive behaviour modification techniques that have been discontinued; we think of the case in front of the College of Physicians and Surgeons where a psychiatrist thought it was perfectly fine to beat and to constrain a psychiatric client and felt that was the practice of the day and therefore it was okay.

So it seems to me that it is at least incumbent upon you to admit that there is a lot of disagreement with this particular kind of treatment and a lot of belief that if it is available for use, there is nothing to control the spread of its use. We would say that if in fact the total ban is to be removed, that there be in place very, very clear provisions for its exceptional use under exceptional circumstances so that in fact that expansion of use can't continue.

**Dr Hamovitch:** I don't doubt that there is much disagreement; anything controversial carries with it disagreement. The question is, who disagrees and what is their knowledge of expertise in this particular area, working with this particular group? Our understanding is that the centre for community living did not contact the Singers or speak with them about what was going on. They certainly did not contact the Ontario Psychological Association. Your office certainly did not contact the Ontario Psychological Association or the College of Psychologists of Ontario, so that, in essence, a body of expertise was not carried into the picture. If you want me to tell you that everyone's going to agree on a controversial treatment, the answer is no. That is true in every area of health care, not just when it comes to aversive stimulation. The fact there is disagreement is not a reason for either including or throwing out a particular piece of legislation.

**Mrs Boyd:** The colleges may not have been consulted, but many registered psychologists who are members of your college were indeed consulted and indeed have written on this issue.

**Dr Hamovitch:** I'd like to know what the particular expertise of those members who were consulted was in this area, because our understanding is that if you look to the experts who have done the research, who are the people living with this and using it, they are fairly united in their opinion on it. In fact, they—

**Mrs Boyd:** They have some vested interest to make sure that they can continue their work and their research.

**The Vice-Chair:** Ms Boyd, I'm afraid I'm going to

have to stop the conversation there. I want to, on behalf of the committee, thank both Dr Berman and Dr Hamovitch for their presentations. We'll move on to our next one.

#### MARGARET RINTOUL

**The Vice-Chair:** The next presenter will be Margaret Rintoul from Carson, Gross and McPherson. You'll have 30 minutes for your presentation and that would include time for questions. You can begin any time.

**Ms Margaret Rintoul:** Thank you for giving me the opportunity to attend. Just so that there are no accusations of conflict and so forth, I am a member of the executive of the Canadian Bar Association, trust and estates, and I have been a member of the interim advisory committee to the ministry for about a year and a half, the mandate of which was to get feedback from a lot of different interest groups in conjunction with the implementation of the Substitute Decisions Act and particularly the policies surrounding the operation of the office of the public guardian and trustee.

I am here today as a practitioner. I am a lawyer. I'm in private practice. I deal primarily in the estates area and, as a consequence, in both planning for incapacity with regard to my clients and dealing with the family members of my clients who have become incapacitated. So I'm here today in the capacity as a practitioner and I'm speaking as a practitioner.

You will hear later on in the hearings from a representative of the Canadian Bar Association and there's a fairly extensive brief that's being presented. I do agree with the contents that are in it, but there are two major issues that I wanted to raise with you today.

One is on the whole concept of capacity assessors and the way they have been established and what is happening in that field right now. The Substitute Decisions Act created the concept of capacity assessors as a defined group. Essentially, the regulation that deals with them says that a capacity assessor is a person who has been deemed by the capacity assessment office to be a capacity assessor, and there's been a training course established. The applicants into that course have been from a very broad area of disciplines.

#### 1530

The difficulty that I and my colleagues are encountering in dealing with cases where there is incapacity and guardianship of some description is needed is that we're faced with the necessity of obtaining one and in some cases two assessments from these capacity assessors. Because the concept is fairly new, there aren't a terrific number of these people around the province. Toronto has a good number of them. Once you get outside of Toronto there aren't all that many of them. We're faced with a lot of delay, a lot of expense and a very cumbersome process, and a lot of it could be solved relatively easily.

The thing which has been flooring my colleagues and myself is that our clients are getting charged hundreds of dollars for these capacity assessments where we, who used to do committee work under the Mental Incompetency Act, were accustomed to paying for reports and affidavits from medical doctors and medical specialists.

We were accustomed to paying \$250, \$300, maybe \$500 if it was a difficult case. We're now faced with the average cost of an assessment being \$600 to \$900 and going on up from there. In large part, it's because the capacity assessors have been drawn from a lot of different areas, they've been given guidelines as to the sorts of things they can charge for, but because it's been created as a sort of market economy, they are permitted to charge basically what they can get paid. The fact is that you're using a market economy that is very new and you're looking at tremendous cost to families, especially where you're not looking at rich people but you're looking at assessments for guardianship of the person.

I have consent from one of my clients to tell you that we got a bill for \$800 for the assessment of a lady who has been in a nursing home for eight years and virtually comatose. It still cost \$800 for a psychologist to attend at the nursing home and decide that this lady needs a guardian. When you compare that with her family doctor who sent a separate \$50 bill for a letter saying, "In my opinion this lady needs someone to make decisions for her," I have to wonder whether the whole concept of having capacity assessors outside of the medical practitioner field is serving anybody's purposes.

The recommendation that I would put forward, and some of my colleagues share it—not all of them, but some—is that there is a lot of good sense involved in allowing a broader classification of medical doctors to be capacity assessors without additional qualifications and training. There are certainly a large number of the medical profession who don't want to do capacity assessments, and there shouldn't be anybody who forces them to do so, but the notion that the only people who can do capacity assessments which will be accepted under the Substitute Decisions Act are those who have gone through this one-week training course and are then designated as capacity assessors is placing an unnecessary burden on the population when these assessments are required.

My recommendation—and this could be implemented quite readily through regulation—would be that certain specialty groups within the College of Physicians and Surgeons should be automatically authorized to be capacity assessors. I would suggest that neurologists, psychogeriatric specialists and psychiatrists ought to be able to do capacity assessment reports. Their evidence is accepted on court applications in any event, even though they're not capacity assessors under the lists that the assessment office sends out.

My recommendation is that the this whole concept of capacity assessors, if this capacity assessment office concept is going to continue, those who are eligible to make assessments for purposes of the act, needs to be vastly broadened.

I know there's been a lot said about the fact that it shouldn't just be a medical model, that capacity covers a whole range of things. I would support the notion that there are people outside of the medical community who can make capacity assessments. But for the vast number of cases where guardianship is necessary, where it is an elderly person, it's a senility, it's a dementia and it's largely a medical diagnosis, there isn't a great deal of

need to go beyond the medical doctor's opinion in order to determine that someone has to take care of this person who has had a massive stroke or who is suffering from Alzheimer's or dementia.

My second element that I'd like to address is the whole issue of the simplification of statutory guardianship. The amendments to the Substitute Decisions Act do go a good deal of the way towards eliminating some of the bottlenecks and the complications that were built into the Substitute Decisions Act.

My recommendation, for what it's worth, is that there needs to be one further step. Under the Powers of Attorney Act it was possible for someone making a power of attorney to specifically include a clause in the document ousting the public trustee from management of their affairs, should they become patients in a psychiatric facility under the Mental Health Act. It was a relatively simple process, when one of those powers of attorney existed, for the person who held that power of attorney to notify the public trustee: "Yes, my father's been committed to this hospital. Yes, I know you're a statutory committee. I have a power of attorney which overrides your authority. Here's a copy of it. I take control." That was an established practice.

The amendments to the Substitute Decisions Act which say that statutory guardianship will not be imposed where there's a known power of attorney and that allow the public guardian and trustee to be replaced more easily as statutory guardian goes a long way, but I'm still hearing from clients: "Can you give me a paper to sign that will mean that the public trustee won't take control of my affairs? I want something that keeps it right out of the government's hands." I have heard that many times.

My recommendation is that there still needs to be some mechanism whereby a power of attorney can be given that specifically states, "In the event that I become mentally incompetent or incapacitated, I have nominated this attorney to take on my affairs and I do not want the public guardian and trustee to be my guardian."

If there was some sort of provision like that and the person who holds that attorney could obtain an assessment to certify that the person is now incapacitated, and from there on the documentation that provides that attorney's authority to operate is the power of attorney plus the certificate of incapacity, then it could be handled privately. The public guardian and trustee's office is not going to be involved in that case, other than perhaps to maintain a record of the fact that this exists. If a client says, "Give me a paper to sign that means that my daughter can manage my affairs and the government won't get involved," I will be able to provide that client with that document. I don't believe it's a great stretch to go one step further, from where the act is currently sitting with the amendments, and allow a power of attorney that specifically ousts the public guardian and trustee.

#### 1540

I think also it would break the bit of bottleneck that is still there, even under the new amendments. One of the big drawbacks with power of attorney—it's been there for years and it's still there—is a power of attorney that is not stated to take effect on incapacity but a power of attorney that's good from day one. That does not prevent



the donor, the person who gave it, from taking any steps they want to as well. The only thing that prevents the donors from taking steps on their own financial affairs is being declared to be incapacitated.

We've got a bit of a bottleneck still in the system where an assessment for statutory guardianship is not to take place unless there is no known power of attorney, which still leaves the attorney faced with an aging relative who is losing his memory, needs care, needs some control on his finances and can't be stopped from pulling large amounts of money out of his bank account. The attorney can't say to the bank, "No, you can't give my father any money," because he's still legally entitled to do so. There's no capacity assessment that says he's incapable; there's no court order, there's nothing. There is only a power of attorney that says, "Yes, I can sign cheques for my father, but he can sign his own cheques too."

If there was something to the power of attorney which permitted the attorney to totally override the public guardian and trustee, and there is a regulation under the Substitute Decisions Act which allows an attorney to seek an assessment, and an assessment given and a certificate of incapacity given to that attorney essentially makes them a guardian, then you could take the public guardian and trustee's office out of the loop except for perhaps maintaining a record that this has happened. But they wouldn't have to get directly involved. You wouldn't have the time on the intake side at the public guardian and trustee's office to assess who is entitled to do this and who is not. Clients would be able to handle things privately, but you would have the ability, on an ongoing basis, for attorneys to deal with their aging relative's affairs with a great deal more certainty, basically.

Those are my points. I'm happy to deal with questions.

**The Vice-Chair:** Thank you, Ms Rintoul. We will deal with a few questions now. Each caucus has about five minutes and we'll start with the Liberal caucus. Mr Grandmaître.

**Mr Grandmaître:** In your first recommendation you say that certain specialty groups should be trained to become capacity assessors. We had another group just before you that said all health practitioners should be trained to become capacity assessors. Can you elaborate, when you said certain specialty groups, on how many groups there would be?

**Ms Rintoul:** I guess my initial reaction to that would be that family practice practitioners, neurologists, psychologists and those in the geriatric specialties, the psychogeriatric specialists, would be the most obvious choices. I would say those who are members of—I'm trying to remember the name of the college—the clinical psychologists ought to be able to do this as well. They're not medical doctors but they're certainly more than adequately trained in that area.

**Mr Grandmaître:** In other words, you do agree that health practitioners should be trained to become capacity assessors?

**Ms Rintoul:** Are you saying all medical practitioners?

**Mr Grandmaître:** Yes.

**Ms Rintoul:** I would question whether all medical

practitioners in all specialties would want to be capacity assessors. A good number of them would decline to be.

**Mr Grandmaître:** It's not whether or not they want to but whether they should be trained to do it.

**Ms Rintoul:** I would not oppose the notion that they should all be trained. I think it would be very difficult to make sure that every medical doctor in the province is trained to be so. That's why my suggestion was narrower and focused more along the lines of those whose specialty training deals in those areas anyway.

**The Vice-Chair:** We have time for one more question.

**Mrs Caplan:** You raised the issue of fees. That's something we hadn't discussed before the committee before your presentation: What's an expectation or a reasonable cost for a capacity assessment, and should that be set by regulation so that there isn't gouging going on and the people know in advance what to expect if they're going to require these kinds of assessments? Certainly, I think people would like to know what the costs are.

**Ms Rintoul:** Right now what is stated is a certain number of guidelines for the assessors. These are guidelines that the capacity assessment office has put out for its own assessors, to my knowledge, and it is something of a marketplace rule. The recommendations are, when you make the arrangements yourself as an applicant or as a solicitor with an assessor, negotiate what the fee is going to be, but that's not always possible. If there are only one or two people in the area where your patient or client lives, then you're stuck with those people and you're stuck with the kinds of fees they're going to charge.

**Mrs Caplan:** What's the range?

**Ms Rintoul:** The statistics that are coming out from the capacity assessment office are that the average is running \$600 to \$900 per assessment.

**The Vice-Chair:** I want to ask you to hold there. We're going to have to move on to the third party now and you'll have five minutes. Mr Marchese.

**Mr Marchese:** The issue of the cost also struck me, because nobody raised this before in this committee. We simply assume these things happen and that naturally there are costs attached, but no one questions what that might have been. It could be an inordinate sum to some people, so that's an issue.

You also raised the issue, could we do assessment in some cases which would involve other practitioners and reduce the number of people who would have to be on that assessment doing the capacity review? By so doing you could cut the cost, I think is what you—

**Ms Rintoul:** No. My point is that there ought to be more, not fewer.

**Mr Marchese:** More, right. I was interested in that and I wondered whether the ministry staff would, not at this point but at some point, have a response to that. I thought that was a useful suggestion you were making.

You raised another point in number 2 that I was interested in, "This objective could be achieved fairly simply by permitting the preparation of a power of attorney which specifically ousts the public guardian and trustee." That seems simple enough. If somebody requests that, why not prepare such a document that would permit that to happen so that the public guardian and trustee is

out of the picture?

**Ms Rintoul:** It would be very nice to be able to do so, but I don't think the statute lets you.

**Mr Marchese:** I understand, but I have a concern I want to raise with you to see what your response would be. In situations where a person might be forced by the guardian to do that, who might have been capable in the past, but there could be possible abuse, and the public guardian and trustee in that situation, if he or she were involved, would see that there is a problem and would be able to intervene, if that person is out of the picture altogether, doesn't that eliminate one more person who could detect a possible abuse situation?

**Ms Rintoul:** I don't know that the way you've got it set up now is going to do that anyway, because right now the person who is named under a power of attorney has total priority in becoming statutory guardian, and the original SDA as it was drafted left some ability by the public guardian and trustee to say, "No, we won't give up guardianship to you, attorney." But the situations where they could do it were very limited and the amount of knowledge they would have to be able to say that was very limited, so for practical purposes there wasn't much they were going to do.

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In the amendments now, which are going almost to the "shall" instead of the "may," if there is an attorney who has power over all assets, they have an absolute ability to become the guardian. An assessment is not going to take place if there is a known power of attorney. That's written right in. And if an attorney comes out of the woodwork after statutory guardianship, the public guardian and trustee gives up guardianship to that person.

I don't know that that's a great deal more safeguard than allowing someone whom you have to—if the problem is, was the attorney valid in the first place because the person lacked the capacity to give it, then that's another problem altogether, and that's not solved by any of the tinkering with the legislation; that's an issue of, is the thing valid to begin with?

**The Vice-Chair:** Ms Rintoul, thank you. I want to move on now—we're on a tight schedule—to the government side.

**Mr Tilson:** Just to follow along with the line of questioning that Mr Grandmaitre raised with the issue of assessors, section 60, I think it is, page 33—

**Ms Rintoul:** You're talking about the original act or the amendment, the bill?

**Mr Tilson:** The amendment.

**Ms Rintoul:** Okay.

**Mr Tilson:** It would allow the government to control the fees of assessors that can be charged for that service, and that has to be remained, of course, because those regulations have yet to be introduced. With respect to the process of training, the designating and the training of assessors and who the assessors should be, I think we agree that there is a need to examine that specific system and your point is certainly well taken, although—and this may have been partially asked before, whether or not your concern would be eased if the regulations defined assessors as including practitioners and including other types of caregivers. I suppose if a physician didn't want

to be necessarily an assessor, well, he or she didn't have to be.

**Ms Rintoul:** No.

**Mr Tilson:** But at least it designates them as that, and there obviously needs to be, as I indicated, before you get to that stage, some sort of process for training those assessors once you've designated them. I suppose my question is, would your concerns be eased if regulations were put forward in that way?

**Ms Rintoul:** I believe that most of these concerns can be addressed by regulation, yes, because the determination of who the assessors are, how they're trained and any sort of fees and so on, as you say, the ability is there now, or will be there, to deal with this by regulation. I think part of my points here are maybe to try to get a bit of a foot in the door on what sort of regulations you consider making.

**Mr Tilson:** An age-old question, I suppose, but it's certainly something that we're continuing to work on. Obviously there's a need in that area, to determine those issues.

Dealing with the second question you raised, with respect to the statutory guardianship and replacement, my understanding is that subsection 8(2) of the bill removes the clause which will cause the power to be terminated if the official guardian and trustee is appointed. That may alleviate your concern. Section 10 goes on to amend section 15 to say that the official guardian and public trustee is ousted automatically if a power of attorney is presented. I think that's set out in section 10.

**Ms Rintoul:** Yes.

**Mr Tilson:** I don't know whether that—it may be I don't understand your question.

**Ms Rintoul:** I'm looking at a little bit broader question here and it deals in part with what a power of attorney is and can do. What the Substitute Decisions Act brought in as a relatively new concept was what they were nicknaming a springing power of attorney, which you could say, "This power of attorney will come into effect only in the event of my mental incapacity." It was a fairly new concept; people have been trying it, but this enshrined it in the legislation.

The policy that was developed in the PGT was to say: "Okay, for that type, we're not even going to let anyone other than the attorney request an assessment except in very extraordinary circumstances and the assessment statement will be given to the attorney. They will then be able to take over dealing." That's fine, but most powers of attorney are not drawn to come into effect only in the event of incapacity, and myself, for one, and a lot of my colleagues don't recommend that people make them that limited because there are lots of cases where an individual needs a power of attorney and the assistance that it can give, even if they are still mentally capable.

The issue, then, becomes, okay, you've got somebody helping out under the power of attorney. The individual can still sign their own cheques and do their own banking and withdraw money from their account, too, which causes its own problems, because as an attorney, you can't tell the bank, "Don't give mother any money," because it's still hers, even though she's taking it out in



large gobs and you don't know what she's doing with it.

The problem that we're facing right now still is that you cannot get the statutory guardianship brought into place if the power of attorney exists, because that's the new amendment, saying we won't assess if there's no power of attorney—

**The Vice-Chair:** Ms Rintoul, I'm sorry, I'm going to have to stop you there. The time has expired and we have to move on. On behalf of the committee, I want to thank you for your presentation. It was certainly helpful.

#### NATIONAL TRUST CO

**The Vice-Chair:** Our next presentation will be Mr Glenn Davis from National Trust. Mr Davis, you have 30 minutes, and that will include time for questions.

**Mr Glenn Davis:** Thank you. I have submitted a very short formal submission. I work at a trust company. There's nothing unique about our concerns that pertain to National Trust. I think our comments could be generic to our industry because we run into these problems—powers of attorney, incapacity issues—in multiple contexts.

First of all, our retail branch systems deal extensively with clients, with powers of attorney presented by family members and other rogues and con men, so we have a lot of concern from our retail people who are trying to protect our depositors. Secondly, we of course are a creditor of people who lose their capacity and become vulnerable. Lastly, I happen to work in the part of the company that acts as executor and trustee and indeed guardian and committee of individuals and power of attorney for individuals. So we see these things in many different contexts.

Generally speaking, the Substitute Decisions Act was a great, welcomed piece of legislation to us, expanding the powers of attorney flexibility, but in a practical sense, we do strongly support some of the amendments, and I guess I'm here to request, in a polite sense, some other relatively minor ones.

My biggest endorsement, if I can, is the amendment taking away the witness statement about the opinion. I'm sure this is not novel. We in fact have instructed our staff not to act as witness on powers of attorney that have this witness statement on it. We are so concerned about the fact that it must mean something and yet nobody can tell us what it means. My own training as a lawyer leads me to read it as implying that the witness has formed an opinion about the grantor's capacity, and in forming that opinion, I think they have to act reasonably. They can't be oblivious or wilfully blind to possible reasons why they couldn't give a power of attorney.

My concern here is that lay people and friends and relatives innocently acting, trying to help by being a witness, may be actually undertaking personal liability for acting as a witness. Certainly if I was in public practice and was litigating a rogue's activity, I would join in the witnesses just so I would have the opportunity to find out what they knew about the person's mental status when they signed the power of attorney.

I know that some very large, reputable law firms insist that their secretaries, who are going to witness the document, sit through extensive portions of the interview where the client's capacity is determined, so that the

secretary is present when questions are asked founding the capacity of the client, so they can later sign the document in good faith. It's a very strong statement. We have no reason to doubt the power to give the power of attorney.

I certainly agree with and understand the desire that witnesses should be cautioned in some fashion to advert to this issue. If that's a policy consideration, I don't have any problem with that. And maybe I'd just toss away the comment that a statutory form of warning to the witness might be sufficient, because that would be a different kind of a thing than what I read as a bit of a warranty by the witness.

In any event, it is certainly a practical problem. If the policy consideration is to make access to these forms easier and cheaper, this witnesses' statement has in fact had the contrary effect.

On a related topic, the expanding of prohibited witnesses, the classes of prohibited witnesses, has had a similar effect. Because of a certain degree of healthy paranoia about who can and cannot be a witness, questions have now been raised, to me directly and indirectly, about whether an employee of a trust company can witness a power of attorney naming the trust company as the attorney. We have many, many clients who have chosen to give a general power of attorney to the trust company, sometimes in preference to family and friends, sometimes because they have no family and friends. To now retroactively raise the uncertainty that these documents are valid is a huge, practical problem.

I think it is a topic that competent lawyers can debate both ways. The attorney named is not the witness. The employee is not the attorney, and in my little submission, I suggest that on a policy basis, it should be made clear that this is not a problem, because trust companies at large are so regulated and audited and have management controls and all kinds of internal controls which make it almost impossible for employees to take advantage of clients' property. The attorney itself, the trust company of course, is never a beneficiary of—well, I can't remember a client making us a beneficiary under their will, for example, and it's so rarely that we're accused of stealing the money, except in a discussion about fees, that it's not really a policy consideration.

**Interjection:** It's a small exception.

**Mr Davis:** A small exception.

So you would do the trust industry and clients a great service through some minor amendment, if there's some way to be found, stressing that where a trust corporation is named as the attorney, an employee is not disqualified from being a witness for that reason.

I guess the underlying theme maybe I'm driving at here is that throughout this legislation, the focus to me seems to be on individual persons, as opposed to corporate persons.

**The Vice-Chair:** Mr Davis, I'm sorry I'm going to have to interrupt you. As many of you are aware, there's a protest going on outside. Security has asked us at the very least to recess for one hour. So it's up to the committee really. We can either recess for the one hour or we can adjourn and try and reschedule.

**Mr Tilson:** I don't think we have any choice. If we

adjourn an hour, you're after 5 o'clock.

**The Vice-Chair:** It's after 5, yes. Okay, so we will adjourn then.

**Mr Tilson:** That's too bad. How will we leave it with this particular witness?

**The Vice-Chair:** I understand that, but security has been adamant that they do want us to—

**Mr Tilson:** Are they asking us to leave immediately?

**The Vice-Chair:** Yes.

**Mr Marchese:** If he could finish his comments, perhaps that would be something that we could do?

**Clerk of the Committee (Ms Donna Bryce):** How much time—

**Mr Davis:** I can wrap up in two minutes.

**The Vice-Chair:** Okay.

**Clerk of the Committee:** We can ask you to come back, if you'd like.

**Mr Davis:** That would be fine too, if it doesn't throw your schedule out. I'm in your hands here.

**The Vice-Chair:** I think it would be unfair to you, actually, if you were asked to wrap up in two minutes without a question period.

**Mr Davis:** I'll be happy to be rescheduled.

**The Vice-Chair:** Okay. We'll do it that way.

Do we have unanimous consent then to adjourn until tomorrow morning at 9 am? Is that a yes? Okay. They're requesting that you leave through the Whitney Block as well.

**Ms Johns:** Do they want us out of the building?

**The Vice-Chair:** Out of the building, right.

So we're adjourned until tomorrow at 9 am.

*The committee adjourned at 1605.*



## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

**Chair / Président:** Martiniuk, Gerry (Cambridge PC)

**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

\*Boyd, Marion (London Centre / -Centre ND)

Chiarelli, Robert (Ottawa West / -Ouest L)

Conway, Sean G. (Renfrew North / -Nord L)

\*Doyle, Ed (Wentworth East / -Est PC)

\*Guzzo, Garry J. (Ottawa-Rideau PC)

Hampton, Howard (Rainy River ND)

Hudak, Tim (Niagara South / -Sud PC)

\*Johnson, Ron (Brantford PC)

\*Klees, Frank (York-Mackenzie PC)

Leadston, Gary L. (Kitchener-Wilmot PC)

\*Martiniuk, Gerry (Cambridge PC)

\*Parker, John L. (York East / -Est PC)

\*Ramsay, David (Timiskaming L)

\*Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Oriole) for Mr Conway

Clement, Tony (Brampton South / -Sud) for Mr Leadston (morning) and Mr Klees (afternoon)

Grandmaître, Bernard (Ottawa East / -Est) for Mr Chiarelli

Johns, Helen (Huron) for Mr Hudak

Marchese, Rosario (Fort York) for Mr Hampton

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service

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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Thursday 8 February 1996

# Journal des débats (Hansard)

Jeudi 8 février 1996

## Standing committee on administration of justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

## Comité permanent de l'administration de la justice

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
Greffière : Donna Bryce



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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Thursday 8 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Jeudi 8 février 1996

*The committee met at 0905 in room 151.*ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

LYLE YOUNG  
GWEN SAMPSON

**The Chair (Mr Gerry Martiniuk):** Good morning, everyone. This is the third day of deliberations of the standing committee on administration of justice on Bill 19. Our first presenter is the Christian Science Committee on Publication, Mr Lyle Young, if you'd identify yourself for the purposes of Hansard.

**Mr Lyle Young:** Good morning. I'm Lyle Young. I am the Christian Science Committee on Publication for Ontario, the public affairs position in our church, a position that has existed since early in the century when one of the meanings of the word "committee" was a single person charged with a responsibility. Beside me is Gwen Sampson, a member of Fifth Church of Christ, Scientist, Toronto, who will be sharing a personal experience.

I'm grateful to appear before the committee today. Studying in Buenos Aires, Argentina, in 1983, the year Argentines got their democracy back, gave me a great respect for the democratic process. Working as a parliamentary intern in Ottawa in 1985-86 increased that respect. I'm glad that the Ontario Legislature internship program still exists.

A little bit more background about myself: In 1987 I became a full-time Christian Science practitioner; that is, someone who gives his or her full time to helping others through prayer. In addition to maintaining my public practice in Ottawa, I became the Committee on Publication in June 1995.

I'm here to tell you that I, on behalf of the Christian Science community, am generally pleased with Bill 19.

But I have one serious concern that causes me to recommend a religious accommodation amendment to the bill. First, though, let me tell you a little bit about the Christian Science church. It was founded by Mary Baker Eddy in 1879 in Boston. It has, worldwide, some 2,000 what are termed branch churches, of which there are 28 in Ontario. Many people in public life are familiar with the Christian Science Monitor, the international daily newspaper published by our church. The Monitor's hallmarks are integrity, objectivity and global perspective. It has won five Pulitzer prizes.

The Christian Science Church was founded to "reinstat primitive Christianity and its lost element of healing." Christian Scientists rely exclusively on a reasoned understanding of God for healing. Specifically, they rely on what they call spiritual treatment. This treatment flows directly and inevitably from their worship of God.

We want to share two examples of this spiritual treatment to illustrate that Christian Scientists have the deep conviction that this form of treatment is treatment. Our chosen religion obliges us, when we are sick, to treat ourselves through prayer or, if we do not readily heal ourselves, to request treatment of another Christian Scientist. Please note that these are religious experiences with an element of physical healing, not clinical accounts. If you'd like to go ahead then, Gwen.

**Ms Gwen Sampson:** In the late 1950s, after having a miscarriage, I was told by the gynaecologist attending me and his partner, who also gave me a thorough examination, that I had a fibroid tumour and should have an operation. This doctor knew that I was a student of Christian Science and was sympathetic towards my religion.

During this period I was receiving spiritual treatment from a Christian Science practitioner and I reported to him the doctor's findings. Because I had been interested in Christian Science for about seven years and I had experienced the efficacy of this healing truth, I decided to continue, with the help of the practitioner, to work out this problem through prayer.

At about this time we had purchased a piece of land and had started to build a new home. This was when I started to question what was truly going on in my experience. It came to me that it was the unfoldment of right ideas within consciousness and not a lot of material things being added. The Bible says, "In him we live and move and have our being." Knowing home to be a divine idea, I knew that it included the warmth of love, the beauty of soul, the colour and harmony of life and the intelligence of mind—love, soul, life and mind being synonyms of God in Christian Science. I affirmed and cherished these ideas, knowing that this was what was

truly going on—not an accretion of good, but an unfolding of God's ever-present goodness.

Some time later, feeling quite free, I ceased to have treatment from the practitioner. Two years later I was examined by the same gynaecologist, who told me there was no sign of a tumour and rejoiced with me that it had been healed through prayer and Christian Science.

**Mr Young:** The second illustration of Christian Science treatment is given by a woman from Navan, just outside Ottawa. These are her words:

"Our first two children were born quickly and painlessly, and there were periods of spiritual growth and happiness. When we were expecting our third child, we prayed to know that God's creation is complete and that God, not man, is the one creator. We felt great love for the child.

"In order to comply with the law relating to childbirth, I visited a doctor. After an examination the doctor explained that the baby, and perhaps I myself, probably would not survive a natural delivery, because the placenta had attached in the wrong place and was completely blocking the baby's exit. He called the difficulty full placenta previa. I was told the birth would have to be by Caesarean section.

"As I drove home I prayed and thought of instances described in the Bible when obstacles had been removed. For example: The times when the stone was moved from in front of Jesus's tomb, when Peter was freed from his prison chains and when the earthquake freed Paul from prison. I also remembered the following verse from Isaiah (66:9): "Shall I bring to the birth, and not cause to bring forth?" saith the Lord. "Shall I cause to bring forth, and shut the womb?" saith thy God."

"I was taking care of two extra children that night for a friend. After I'd put them all to bed and was cleaning up, I found myself singing the following lines from hymn 148 in the Christian Science Hymnal, 'Green pastures are before me, Which yet I have not seen.'

"I spent the rest of the evening in prayer. The next morning I called a Christian Science practitioner and told him the situation. Many helpful ideas were shared in the conversation, and I gained a better sense that the material evidence was a lie, not the truth, about God's child, and that God's law is always at work, maintaining man's spiritual perfection. I saw that I must know only what God knows and hold to that perfect idea. At this point I felt completely at peace.

"Prayerful work continued, and I became aware one day that the obstruction was moving. This was painful at first, but with the prayerful help of the practitioner the pain quickly ceased.

"When the next examination came, the doctor was very surprised to find that everything was fine. A few weeks later a dear baby girl was born normally and quickly. She is a perfect joy."

You might be interested to know that the woman is a very active homemaker and has played a strong role in the Girl Guide movement.

Our specific concern with Bill 19 is clauses (b) through (h) under the exclusion of treatment in the Health Care Consent Act. We consider these provisions to be directly adverse to Christian Science treatment and thus

to our freedom of religious beliefs and practices, as recognized by section 2(a) of the Charter of Rights and Freedoms.

Let me talk about the clauses that we find most invasive; first, "(b) the assessment or examination of a person to determine the general nature of the person's condition." Science and Health with Key to the Scriptures by Mary Baker Eddy—and I've placed several copies of the book around so that you're welcome to have a look at the book or to even follow these passages that I'm quoting—is the definitive and complete statement of Christian Science and Christian Science treatment. Here is a quote from page 421, "If you would destroy the sense of disease, you should not build it up by wishing to see the forms it assumes." Do you see that this is the precise opposite of clause (b)? Clause (b) says that the health practitioner examines the person to find out if there is disease and then perhaps assesses it. The statement from Science and Health says that going looking for disease is not the way to cure disease. Rather, one of the major themes of this book is that by searching for wholeness and wellness we find these instead.

Let's consider clause (d), "the communication of an assessment or diagnosis." Again, quoting from Science and Health, page 370: "A physician diagnosis of disease...tends to induce disease." Thus, a Christian Scientist would view this clause as both adverse to his religious beliefs and to his health.

Let's go to (g), "a treatment that in the circumstances poses little or no risk of harm to the person." Science and Health says this on page 167: "The scientific government of the body must be attained through the divine mind." "Divine mind" means God in this context. "It is impossible to gain control over the body in any other way. On this fundamental point, timid conservatism is absolutely inadmissible. Only through radical reliance on truth can scientific healing power be realized." Again, truth is a synonym for God in our religion.

This passage brings out that Christian Science treatment cannot be mixed with other forms of treatment. Another treatment, whether or not it was thought to pose risk, would infringe this religious teaching. As you might imagine, Christian Scientists would be strongly opposed to "(h) anything prescribed by the regulations as not constituting treatment," for obvious reasons.

Let me summarize. Christian Scientists have practised what they term "spiritual treatment" for almost 120 years. That treatment is integral to their worship of God. Exclusions (b) to (h) under the definition of treatment are adverse to that spiritual treatment and so adverse to our religious beliefs and practices. Thus we think that we have strong grounds to recommend that a religious accommodation be included in this bill.

We recommend the inclusion of the following religious accommodation amendment as section 7 under the general section at the start of the act: "Notwithstanding the exclusions listed in paragraphs (b) to (h) of the definition of treatment, a health practitioner who has reasonable grounds to believe that a person wishes to rely exclusively on treatment by prayer and spiritual means as an enjoyment or an exercise of a religious freedom, shall not, without the explicit consent of the person or the



person's substitute decision-maker, take any of the actions specified in paragraphs (b) to (h) of the definition of treatment." We propose the marginal note, "Enjoyment or exercise of a religious freedom." This phrase is used in the Drugless Practitioners Act, 1990. If that marginal note is too long, simply "Exercise of a religious freedom" would be just fine.

Concerns about legislative incursions on the right to Christian Science treatment are not new. There is a protective reference to spiritual treatment in the Drugless Practitioners Act, 1990. That reference has been there since the passing of the Drugless Practitioners Act, 1925. In addition, the Regulated Health Professions Act, 1991, includes a religious accommodation provision, as did its predecessor act, the Health Disciplines Act, 1974. The words "Christian Science" are actually used in An Act respecting the Regulation of Nursing, 1991.

There are three other reasons for adopting this religious accommodation amendment. First, as we heard Tuesday from the College of Physicians and Surgeons of Ontario, health care practitioners should have maximum clarity in this legislation. Why should they risk their livelihood to leaving themselves vulnerable to liability?

Second, it could be argued that individuals not wishing to be subject to paragraphs (b) to (h) are already protected by common law. This may well be, but are a person's religious beliefs and practices really protected if that person has to potentially spend \$100,000 to go to court to get those rights recognized? Why not include this amendment and make health care practitioners and those wishing to rely on spiritual treatment both happy?

Lastly, the court system in Ontario is overburdened. Why not make the taxpayers of Ontario happy by making this point of the act as lucid as possible and thus saving them additional costs to the system by preventing needless litigation?

Thank you very much. I'd be delighted to answer any questions.

0920

**The Chair:** Thank you, Mr Young. We'll start with the third party.

**Mrs Marion Boyd (London Centre):** I was interested in the examples you gave of the inclusion of other such references. I'm curious about whether you came to committee and made presentations on that at the time or whether that was automatically included in those acts, because I can't recall, in the ones that we passed during our time in office.

**Mr Young:** I just came to office myself in June, so I'm not perfectly aware of what's been done before. I do know that Christian Science Committees on Publication like myself have been making representations to the Ontario Ministry of Health ever since at least 1925. We feel that's very important. We publish and distribute among members of our church this fairly big book entitled *Legal Rights and Obligations of Christian Scientists in Ontario*. So our freedom to practise the religion that we feel called to practise is very important to us, so much so that we're willing to devote quite a number of resources into making presentations like this one.

**Mrs Boyd:** You've made the point that you believe this answers the request that physicians have made, that

the act be as clear and as protective of them in terms of liability as possible, and you believe the suggestion you've made about an amendment would accomplish that. Have you had any discussions with the OMA or the college?

**Mr Young:** No. To be honest with you, I haven't.

**Mrs Boyd:** Okay. I just wondered whether you had. Thank you.

**Mrs Helen Johns (Huron):** I just wanted to draw to your attention section 19 of the act. It says in this section:

"(2) In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

"(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable."

I believe that takes into effect a number of the issues you're talking about. That was in the Health Care Consent Act, subsection 19(2), and then also clause (a).

**Mr Young:** But with all due respect, just looking at that again very quickly now, it seems to me those relate to treatment. But we're not talking about what the bill qualifies as treatment; we're talking about the things that are excluded from that category.

**Mrs Johns:** So your concern is that "treatment" has a specific definition and that there are some things outside of treatment that you're concerned about?

**Mr Young:** Right. To summarize my arguments again, Christian Scientists feel that they practise spiritual treatment, and that's integral to their religion. The things that I went through there, the things that are excluded from the definition of "treatment," are very invasive to that practice. We wish a religious accommodation not to have those acts that are considered non-treatment performed on us, should we find ourselves in a hospital.

**Mr John L. Parker (York East):** Thank you very much, Mr Young, for your presentation this morning. I'd like to ask a question that actually doesn't arise directly from your remarks this morning, but I wonder if you could help us out with it.

**Mr Young:** Sure. I'll do my best.

**Mr Parker:** We've received a lot of expressions of concern over the current regime for proving a power of attorney, the process of validating a power of attorney before it can be used. I know that you have written on that subject. Can you help us out with your thoughts on that?

**Mr Young:** The way the new act has come in, I think it's perfectly fine in that regard. I certainly don't have any qualms about it. The fact that you can choose your method of assessment, I feel quite happy about that. I think that's good, because from the standpoint of a Christian Scientist, a Christian Scientist could choose another Christian Scientist. You see, sadly, occasionally Christian Scientists are interpreted as not being mentally capable, because again, they believe in radical reliance on God. Occasionally, I'm sorry to say, health professionals sometimes don't equate that with sanity. So there really is a great need for there to be strong protection in the legislation, we feel.

**Mr Parker:** If I could just be clear: You are uncomfortable with the current regime, but the present bill addresses your concerns adequately?

**Mr Young:** No; the present bill does not. I take great issue with, on page 66, clauses (b) through (h), that are excluded from the definition of "treatment."

**Mr Parker:** I understand that, but on the question I'm asking about validating a power of attorney, where in the present bill we have removed the elaborate provisions for validating a power of attorney, I understand from your remarks that you're comfortable with the amendments we've made there.

**Mr Young:** Yes. The only aspect of the bill that is of concern to us is this, because we find it highly intrusive.

**Mrs Elinor Caplan (Oriole):** If I could, I'd like to go over with you where I think there are protections, and if you believe that these are inadequate, I'd like to discuss it further.

Frankly, I agree with Mrs Johns. I think that section does provide some assurance to you. However, there are some other things in place that I think you should be aware of and I hope you are: the fact that competent adults have a right to refuse treatment. In other words, a professional cannot do anything to you without your consent.

**Mr Young:** Right, but we're not talking about treatment here. We're talking about things that are excluded from the definition of treatment.

**Mrs Caplan:** Things that are excluded. Under the Regulated Health Professions Act there are harmful acts which are listed, and anything that is outside of that, practitioners, whether they be religious practitioners or anyone, are free to offer.

Those which are harmful are listed under that legislation. We've used words like "treatment" and we've had debates about what is treatment and what is not, but what we're talking about now are the things that pose a risk of harm. I think the only one in that list that you probably would have some difficulty with would be the—

**Mr Young:** No, ma'am. With all due respect—

**Mrs Caplan:** No? All right. I'm trying to understand.

**Mr Young:** Yes. With all due respect again, some of these, and it perhaps is not too strong a word, are positively inimical to our practice of our religion. We're not concerned so much about what you do to us physically—of course, we're concerned about that—but we're concerned too as Christian Scientists about what happens mentally, because what happens mentally is at the root of our religion.

**Mrs Caplan:** I understand.

**Mr Young:** For example, the item where it says "the communication of an assessment or diagnosis"—for a Christian Scientist to have a detailed explanation of sickness, that's completely anathema. That's extremely invasive.

**Mrs Caplan:** I guess the point I would make is that you can choose the practitioners you wish and discuss with them your desire not to have that communication or to have it in whatever form you want.

**Mr Young:** Imagine this scenario, where a Christian Scientist is taken in an ambulance to a hospital. He is non-ambulatory, perhaps he can't speak, but there's no

particular emergency and the doctor says, "Well, we've taken some X-rays and here's what the problem is."

**Mrs Caplan:** If the person is unable to speak or is in any way judged incompetent and has written a power of attorney and designated someone of a like faith to act on his behalf, then that communication wouldn't take place with him at all. It would be with someone on his behalf. If he were competent and that's—I'm having trouble understanding what your expectation would be.

**Mr Young:** But again, the substitute decision-maker—

**Mrs Caplan:** In other words, are you saying that no one should be able, in an emergency situation, to talk to the patient?

**Mr Young:** No. We have no qualms about the emergency things. They seem to us reasonable. What we have qualms about are the things that come under the definition of not being treatment. We have very special needs, we think, and we have had those for 100 years. Allow us to be excluded from that. Christian Scientists aren't interested in receiving a diagnosis.

**Mrs Caplan:** My view is that those protections are here for you, because in a non-emergency situation you can choose not to have contact with the practitioner. You can say: "I don't want you to treat me. I don't want you to talk to me. I'm going to find somebody else." If you are unable to speak, you can have a power of attorney who will say, "This is the person I have the power of attorney for, and he is not interested even in—"

**Mr Young:** Are you of the view that health care practitioners in general are so sensitive that they will not give an assessment or a diagnosis? I'm not of the view that they will think that's a problem with anybody. If it's written in the legislation, they will say, "Ah, this is a special case"; otherwise they won't imagine it's a problem at all, whereas for us it is a deep problem. It is an invasion, and it's an invasion of our rights to practise the religion that we want to practise.

**Mrs Caplan:** Certainly, I don't think anyone wants to interfere with anyone's right to practise their religion. I want to be really clear on that. I don't think it's the intent of the legislation.

**Mr Young:** No. I thoroughly agree with that.

0930

**Mrs Caplan:** I think that what's been attempted over the years is to put in place safeguards so that you could opt out of having treatment imposed upon you or even having communication with a practitioner if you choose not to. There are many who choose alternative forms of therapies and that is their right. No one says to them, "You can't do that," unless someone is offering something which runs contrary to the legislation on the things that are harmful, in which case those are licensed to certain professionals. So I am having some difficulty understanding, in a non-emergency situation, why you wouldn't just say: "I'm out of here. Thanks very much. I'm not interested in what you're offering."

**Mr Young:** It's that in our view the health care practitioners, well-meaning though they are, may not be sensitive to the fact of how inimical to our practice is a description of disease. They may just, without even knowing it, say, "You've got this," whereas a Christian Scientist would say: "Thanks a lot. I didn't want to know that."



**Mrs Caplan:** The position I take is that you can just say: "I don't consent to having you as a practitioner," period. "I don't want to have anything to do with you. I'm out of here." If you've fallen and sprained your ankle and they come and you don't want them, you can say, "I do not consent," period. Once you do that, whether they're sensitive or not, they have no right to any further treatment, communication or anything else if you do not consent to that, and then you can complain to the college.

**Mr Young:** Yes, okay. But why should we have to go through all the litigation to determine that? Why not just include this and make things easier?

**The Chair:** I have a question. Are you saying that the objection is that a medical practitioner would provide a medical opinion to a Christian Scientist?

**Mr Young:** Quite possibly, without being sensitive to what he or she is doing.

**The Chair:** And you want to prevent that.

**Mr Young:** Exactly.

**The Chair:** Thank you, Mr Young. That is the half-hour.

**Mr Young:** Thank you kindly.

**Mrs Caplan:** Mr Chairman, as the next presentation comes forward, would now be a good time for me to table Mrs Ginsberg's remarks from yesterday?

**The Chair:** Yes.

**Mrs Caplan:** It will take just about a minute and a half while the others are coming forward. These are not my words, these are the words of Etta Ginsberg-McEwan, who addressed the committee yesterday. She said:

"I did not have the time to make two important points. The first point is the one that was raised by several members of the committee on Monday with the public guardian and trustee agency regarding conflict of interest. While most families are loving and caring, I can tell you from my many years of experience as a social worker that there are those adult children who 'wish to get their hands on their parents' moneys.' There is physical, financial and emotional abuse.

"Please press on that the rights of older people and children and young adults with disabilities do not get compromised by 'well-meaning friends and families.'

"The second point I want to make is that Mr Wilson should not be so quick to appease the doctors because he has taken them on in other areas. You need to know that doctors 'not all' are not our advocates. Older people are being thrown out of hospitals prematurely and being forced into low-standard nursing homes. Older people are threatened day after day in our hospital system. Their situation could be improved with an advocacy organization."

Signed, Etta Ginsberg-McEwan.

**The Chair:** Thank you, Mrs Caplan.

#### TORONTO MAYOR'S COMMITTEE ON AGING

**The Chair:** The Toronto Mayor's Committee on Aging—Ms Neely is the chair. If you could identify yourself, if you're going to be making a presentation, for the purposes of Hansard.

**Ms Lois Neely:** Ladies and gentlemen, I'm Lois Neely, the chair of the Toronto Mayor's Committee on Aging.

My background in the field is that I was for 20 years administrator of a long-term-care facility in the province of Ontario. I was born in Toronto, I've lived here all my life and I live in downtown Toronto now.

I'm glad to have with me our coordinator from the Toronto mayor's committee, Margaret Bryce; also our counsel, Judith Wahl, Advocacy Centre for the Elderly. The presentation to the standing committee is as follows.

The Toronto Mayor's Committee on Aging is grateful for the opportunity to appear before your committee to talk about the needs and rights of elderly people, but we regret that we have come here so often. We came here in 1992 to offer suggestions and to support the Advocacy Act, the Substitute Decisions Act and the Consent to Treatment Act, the acts which are now being amended or repealed.

These three acts recognize that competent people have the right to make decisions about their lives. We support that. These acts give competent people a mechanism for turning over the decision-making power to another competent person of their choice. We support that. These acts also set out a process for taking away the right to make decisions. The current legislation provides a number of safeguards. We support that too.

The Toronto Mayor's Committee on Aging knows that family and friends are an important resource to elderly people. They provide more than 90% of the loving care that people need as we get older. But the Toronto Mayor's Committee on Aging also knows that relationships can break down over time and that sometimes family members are not physically and emotionally capable of looking after their older relatives, and sometimes people abuse the love and trust which they shared many years before.

The Toronto Mayor's Committee on Aging has been a leader in Ontario in talking about the scandal of elder abuse. We are proud that we started campaigning in 1984 and we're proud that we have continued to provide resources to raise awareness of this issue. We have a video which is available in English and French, a T-shirt, pamphlets in five languages; we're now producing a book-mark which will be available in English and 12 other languages. You will notice that our slogan on your book-mark which you have is "Home is where the hurt is." That's a very painful message.

We would all prefer to believe—I'm sorry; I'm a senior myself—that all families love and care for each other and that they will always act in the best interests of their frail family members. I can tell you from my 20 years' experience that this is often abused. Most of the time children are wonderfully caring, but I could tell you specific instances which say that children can be consumed by greed and not act in the best interests of the senior.

We're here today to offer suggestions, but very little in the way of support, for the changes which are being proposed in this bill. We're concerned that the government, through this Bill 19, is proposing to withdraw some important safeguards and thereby potentially put frail, elderly people and people with disabilities at risk. We would like to know why you're in such a hurry to change the legislation and why you're in such a hurry to take

away the rights of elderly people and people with disabilities to make decisions about their own lives.

Bill 19 repeals the Advocacy Act. The government believes that the Advocacy Commission is too expensive and that its powers are too wide. We protest. The Toronto Mayor's Committee on Aging believes that people who are vulnerable to abuse may need help to make their own decisions. They require information on their rights and on the options which are available to them, and they require people who can help them to deal with the issues in culturally appropriate ways.

The Toronto Mayor's Committee on Aging recommends that money be allocated for a program to provide grants to legal clinics and community organizations and to establish an office to provide training and information to those community organizations.

We also recognize the important role that the Ontario Advisory Council on Senior Citizens and its companion council on people with disabilities played in advising the government on issues affecting seniors and people with disabilities. We regret that these valuable advocacy organizations were terminated.

We find the recommendation from the Advocacy Commission that a non-profit corporation be established to administer advocacy activities worthy of support. We believe that senior citizens should be included on the board of directors and that the board should not be restricted to people with disabilities.

As to the Substitute Decisions Act, although that act was passed unanimously by the Legislature, it has been the target of attacks by the press, community groups and the Conservative Party. Unfortunately, most of these attacks were based on misinformation. The legislation had been in force for just 10 months. It's unfortunate that extensive changes are being made at this time.

The Substitute Decisions Act sets out the rules for giving and using powers of attorney. It also sets out the rules for taking away a person's right to make decisions. Because this act deals with questions of personal liberty, it sets out a number of safeguards for these processes. Many of the safeguards are removed in the proposed legislation. We note the following problems with this part of the bill.

#### 0940

(1) The current legislation prohibits paid caregivers from the role of attorney for personal care. The new legislation not only permits paid caregivers to apply to the court to be a guardian for personal care, but also gives the paid caregivers priority over the public guardian and trustee. We believe that this bill permits a dangerous conflict of interest. This amendment does not protect the interests of the frail elderly and other vulnerable people.

(2) The new legislation will permit a child of the person giving the power of attorney to be a witness to the signing of the document. We believe that this provision condones a conflict of interest.

(3) The witnesses to the power of attorney will be exempt from the current requirement to sign a declaration that they have no reason to believe that the person assigning the power of attorney is incapable. We believe that this important safeguard should be retained.

(4) Although existing powers of attorney will continue to be valid, they will be valid under the terms of the new act, not under the old. Certain premises and protections of the old act will be withdrawn. We do not believe that this provision is in the interests of elderly people who have already completed valid powers of attorney in good faith.

(5) The bill removes the requirement that a power of attorney for personal care which was given with conditions be validated before it is used. It also removes the requirement to inform the person involved that you are starting to make decisions on their behalf. We believe that this is an intolerable abrogation of our rights and liberty.

(6) The bill does not introduce any new ways to protect the property of vulnerable people. When people are assessed as incapable of making decisions on medical treatment, there is no onus on the doctor to report this situation. There is no easy way to have a person assessed for incapacity.

The current regulations provide that a person requesting an assessment for incapacity to manage property pay an independent assessor to undertake an assessment. We are advised that the average cost of an assessment is \$750. Individuals who are worried about their friends or tenants and physicians and social workers who are concerned about their patients and clients cannot afford that kind of fee. We need something better to deal with this.

This bill repeals the Consent to Treatment Act and replaces it with the Health Care Consent Act. We believe that the bill gives unnecessary power to the medical profession and makes it easier for families to intervene prematurely in the lives of the frail elderly and other vulnerable people.

(1) The bill removes the most basic guarantee in the present act, that a patient be informed that their right to make a decision is being taken away from them. We believe that doctors owe it to their patients to inform them of a finding of incapacity; it's unethical not to do so. We believe that this provision is a gross infringement on the rights of the frail elderly and other vulnerable people.

(2) We are concerned that the legislation will permit members of six listed health professions to evaluate an elderly person's capacity to consent to admission to a long-term-care facility. This is a very important decision in a senior's life. We do not believe that it should be removed by the signature of a speech therapist, a physiotherapist, occupational therapist, nurse, or even on the signature of a doctor or psychologist, unless they are directly involved in providing the care requiring residence in a care facility. Dermatologists, surgeons and ophthalmologists may provide excellent care, but they are not qualified to assess the capacity of elderly people to make decisions about where they live unless they have been involved in providing the care.

(3) We also recommend that people who assess capacity be trained in university and by their hospitals and professional colleges for this role and that appropriate standards be established for these assessments.

(4) We are concerned that this bill allows a health care facility which has obtained consent to treat an elderly person to move that person to another facility and to



provide that treatment there. We believe that this section will be used to move an elderly person to a long-term-care facility without their consent, even though such consent is guaranteed in the Long Term Care Statute Law Amendment Act.

(5) We are concerned that the bill proposes to allow substitute decision-makers to consent to the use of electric shock therapy. The Toronto Mayor's Committee on Aging is opposed to the use of ECT as a restraint for elderly people. Almost 40% of the electric shock therapy provided to residents of Ontario in 1993-94 was given to people over the age of 65, although seniors constitute less than 12% of the population—40%. We believe that this abuse of the elderly must be curbed. Electric shock therapy should require the consent of a court.

Ladies and gentlemen, the press release accompanying the tabling of this legislation says that it will "give more power to families in the care and protection of their mentally incapable relatives." The Toronto Mayor's Committee on Aging believes that families do not need more power, frail people do. We ask you to reconsider this legislation and allow more opportunity for consultation.

**Mr Tony Clement (Brampton South):** Thank you very much for your presentation. You've obviously put a lot of thought into it, and it's important that we all, as a committee, understand where you're coming from, so I thank you for taking the time to appear before us.

As the parliamentary assistant to the Minister of Citizenship, Culture and Recreation, I want to focus my questions on the repeal of the Advocacy Act, which you've referenced on page 2 of your brief. As a preamble, though, could I just talk about the winding down of the advisory councils you mentioned?

I guess we're of the view—I want your comment on this to see whether from your perspective we're on the wrong track in thinking this way—that when these councils were created 20 or 25 years ago, there was not a lot of advocacy going on for seniors or persons with disabilities. Fortunately for our society, that has changed. There are a lot of vocal, well-organized and articulate advocacy groups in place, many of which we've already heard from in this committee process, and so we felt we were replicating what was out already there and in fact what we were partially funding in the advocacy world. From your perspective, are we still on the wrong track by thinking that?

**Ms Neely:** Yes. I was a member of the advisory committee on seniors years ago when I was in the field. I felt then we served a very valuable use. I feel they still would, because they're central. We're all over the province and we don't have a good enough alliance, whereas we felt when they were in place, we could go to them and we felt maybe they had a direct pipeline to you people. They were a little more in touch and could keep us on course a little better. I think you could establish a seniors' advisory council. It might not have to cost as much as it did in the early days. I know we had a lot of people on the committee and we probably spent a lot of money in those days. It doesn't have to be the style we were in the freewheeling 1960s and 1970s, but I do believe it would serve you very well.

**Mr Clement:** I thank you for your input on that. Could I turn then to the Advocacy Act, because it was a position of our party, as you recognize, before the election and during the election that we were going to wind down the Ontario Advocacy Commission—I guess I can put it that way—and repeal the act. We're kind of committed to that, but we are very much interested in making sure that in our society advocacy is done in a way that is equitable and just. I'm looking for your input. Is there a way that we as a government can assist in the education of advocates in ensuring there are high-quality advocates in the volunteer community and among our friends and family? Is that something you'd like to see us consider?

**Ms Neely:** Point 3: We'd go along with the recommendation from the advocacy committee that a non-profit corporation be established.

**Mr Clement:** Does it have to be that way, though, or can it be through another program that may accomplish the same goals? I'm trying to focus in on the end result rather than the means of getting there, I guess.

**Ms Neely:** Right. No, I think we agreed that was a good idea and we say to make sure senior citizens are there. I don't think you're making enough use of the good, retired senior citizens who could be \$1-a-year men and serve you very well—

**Mr Clement:** And women.

**Ms Neely:** —especially when more and more are getting put out to pasture earlier. It gives them a little status, a little position, you know, recognition. Put them to work for you. They could serve you very well without a lot of bucks.

**Mr Clement:** I think that's an excellent idea. I thank you for your suggestion.

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**Mr David Tilson (Dufferin-Peel):** Obviously you are at odds at least with our party with respect to the Advocacy Commission, and I respect your position on that. This debate has been going on for a substantial period of time. It's gone through two sets of hearings. Individual MPPs from all parties have held town hall meetings or forums in their own ridings to debate this. There have been discussions in our own individual offices. Particularly for those who are re-elected to the Legislature, it's been an ongoing debate with respect to the Advocacy Commission for some time.

My personal experience is that I have a mother who is in a nursing home in Orangeville and I have a great deal of respect for the nurses and the health care providers in that institution. They provide absolutely wonderful advice to seniors, some of whom are incapacitated or on the verge of incapacity, some of whom aren't. It's a combined nursing home with retirement home and it's an absolutely wonderful facility. The advice they give to seniors is outstanding and I challenge anyone who wishes to criticize the advice that comes to those situations.

There are many health care providers who have said to me and other politicians of all three parties that they were concerned with the interference that would take place by the advocates who were going to come out of the Advocacy Commission, to interfere with advice that is already going to be given. They were concerned when seniors, because that's what we're talking about here, who were

competent signed powers of attorney authorizing members of their family, whether it be children or others, to look after them when they were incapacitated, whether that be permanent or temporary—concerned at the interference of the advocates that would take place as a result of the former legislation, the legislation that exists now. They were very concerned with that interference.

There is no question that there is abuse of people in our society, and I guess that's one of the questions we all have a concern with, whatever our political faith is, as to how we're going to deal with that abuse, whether it be against women, against children, against seniors, and that whole array of issues.

**The Chair:** Your time's up, Mr Tilson.

**Mr Tilson:** I can simply say that our philosophy is different as to how we're going to solve the problem.

**The Chair:** Everybody's ignoring me. Mr Tilson, your time's up.

**Mrs Caplan:** Thank you for an excellent presentation. Were you consulted by the government? You're an advisory committee, I know, to city hall, and I'm wondering whether you were involved in any of the consultations the government had prior to the tabling of this legislation for first reading.

**Ms Neely:** Not that I'm aware of. I'm a new chair.

**Ms Margaret Bryce:** No.

**Mrs Caplan:** I've asked that question of a number of people. I've forgotten, actually, due to lack of time, to ask a number of others. Judith is here, if I could direct a question; it relates to consultation. You mentioned that you're involved with the interim advisory committee and we heard from Ms Bregman on February 6 in the morning about participation in what was I understood part of the consultation, a meeting that took place on January 23. It's come to my attention that in fact that was an information meeting on the implementation of the legislation. Was that a consultation meeting as far as people having the opportunity to offer suggestions for changes to the bill was concerned?

**Ms Judith Wahl:** On January 23?

**Mrs Caplan:** I understand there was a meeting.

**Ms Wahl:** Oh, there was a meeting of the interim advisory committee.

**Mrs Caplan:** Yes.

**Ms Wahl:** That wasn't a consultation meeting. The committee was meeting to provide advice to the office of the public guardian and trustee on the implementation of Bill 19 as it stands, on the assumption they would have to move quickly and be prepared to make changes in the way things are operating. It was intended to provide some advice.

**Mrs Caplan:** Given your involvement, are you aware of any formal consultation that took place, particularly on the health care consent legislation?

**Ms Wahl:** I was not involved in any consultation on the health care consent legislation. I'm not aware of any.

**Mrs Caplan:** I'm trying to find out who was consulted and it's a tremendous frustration.

**Ms Wahl:** I can only speak for myself. I was not consulted.

**Mrs Caplan:** You were not consulted on that either.

**Ms Wahl:** On the Health Care Consent Act, no.

**Mrs Caplan:** One concern you raise that I've been raising day after day has to do with the right of people to be told when they're found incapable and that decisions are going to be made on their behalf by someone else. You put it extremely well, but you also raise the issue of electroshock therapy. The position I have taken, and I'd ask for your comment on it: The previous government brought in an absolute ban and we've heard some really heartbreaking stories, particularly about one young man; for him it was a last resort and everyone agreed it was an appropriate therapy. Relating to these statistics around electric shock, are you referring to faradic stimulation or psychiatric electroshock therapy?

**Ms Wahl:** What was the first one?

**Mrs Caplan:** That's the faradic stimulation. I hate the term but—

**Ms Neely:** No, we're referring to electric shock therapy, period, which is being used to control behaviour. We object to anything being used to control the behaviour of the elderly, whether it's medication or whether it's shock treatment.

**Mrs Caplan:** We were told this electroshock therapy was only available in Community and Social Services facilities and it was limited—

**Mrs Boyd:** That's faradic.

**Mrs Caplan:** That's faradic. Could you explain the difference? I must admit, I think there are people, including myself, who would like to know which therapy you're referring to. I haven't heard about this. Is this for mental illness?

**Ms Wahl:** My understanding of what the Toronto Mayor's Committee on Aging is expressing is that it's all electric shock therapy. They're not talking about just the faradic stimulation. I understand faradic stimulation is for the purpose of behaviour modification.

**Mrs Caplan:** This electroshock therapy you're referring to is not the one that psychiatrists use in the psychiatric facilities?

**Ms Wahl:** They're referring to it as all, all ECT.

**Mrs Caplan:** Is there anything else between that one and faradic stimulation that we're not aware of?

**Ms Wahl:** I don't know.

**Ms Neely:** The statistics speak: 40% of it gets done to people who are not terribly defensive about these things. As to the advocacy, may I just say back to that, that we made the point that so long as somehow this—you are, I believe, in government as elected representatives, and so long as you provide some legal aid for seniors who are desperately in need of help, which is our first recommendation under the Advocacy Act.

**Mr Rosario Marchese (Fort York):** Thank you for the presentation. I think your experience—not just yours but people like you have a long history in the field, and you've said you're now senior, and you've seen and witnessed a number of abuses that can happen to people and you've outlined a series of problems and suggestions. I think it's important for the government members to listen to people like you because when you talk to us about your experiences, it's important for us to listen to them and understand what you're saying.

On the whole issue of the Advocacy Act, they've been arguing that the Advocacy Act and the commission are



too intrusive. A number of people have said that these advocates and these rights advisers operate under the provisions of the advocacy service, which is to help individual vulnerable persons to express and act on their wishes. That's hardly intrusive. When people are there to represent vulnerable people to express and act on their wishes, that's not an intrusion, obviously; also, to help vulnerable persons to bring about systemic changes at the governmental, legal, social, economic, institutional level.

The point of that is that what we're trying to get at is systemic problems across the board. Volunteers can't get to systemic problems. Little organizations that have very few paid staff can't get to these systemic problems.

Mr Clement is very happy when you talk about using volunteers and seniors as a richness of capital and all that, because that's what they want to get to, but I don't believe that's adequate, to rely on volunteers and to rely on poorly paid services where they don't have full-time staff to get to some of the abuses that have happened to people with disabilities and seniors. Do you agree with that?

**Ms Neely:** Yes, I believe this is so. I think we made our point. First, our wish is that the government weren't moving quite so quickly, that we'd give it a little bit longer than 10 months. Certainly everything can be abused, but it just seems to be a little bit of a hurry. Yes, I don't think the government's suggesting that volunteers can do it all. There has to be a little funding here.

I wish all the homes were as good as the one Mr Tilson has mentioned. There are still homes, I'm afraid, in the province that people wouldn't put their dogs in. That's been the case and I'm afraid it's going to go on that way. We do need some training to help the frail elderly and the frail disabled. We need trained helpers to do this. This is what we're asking for.

**Mr Marchese:** I have a quick point. I'd like to ask Mr Tilson this question, as the parliamentary assistant, because a number of people have made this comment around paid caregivers as guardians, and they've highlighted this as a particular problem. This particular bill gives priority to caregivers over the public guardian and trustee as a court-appointed guardian.

**Ms Neely:** Yes; very, very dangerous.

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**Mr Marchese:** We have no rights advisers who would give guidance and identify possible abuses; there are no requirements to produce financial reports either, which further complicates possible abuses; and the elimination of restrictions on the use of restraints—all of these things are now in this bill. Given what a number of people are saying, have you thought about either the elimination of that or a change in that?

**Mr Tilson:** I don't know whether this is the appropriate time to get into clause-by-clause discussion.

**Mr Marchese:** Yes, it is. I'm asking you, Mr Parliamentary Assistant, as you used to do in the past.

**Mr Tilson:** But if Mr Marchese wants to yield the floor to me to allow me to give a speech, I'll be pleased to do that.

**Mr Marchese:** Mr Tilson, you have asked those questions in the past when you were here. I'm asking you to answer them as briefly as you can.

**Mr Tilson:** If you wish me to talk at this time, sure. The answer to your question is that, again, I'm going to repeat what we've already said, that the Advocacy Act is—

**Mr Marchese:** No, I'm not talking about the Advocacy Act. This is a different question. Just speak to this, please.

**Mr Tilson:** All right. With respect to the keeping of records, again—

**Mr Marchese:** No, the paid caregivers as guardians. Speak to that one, please. That's the question.

**Mr Garry J. Guzzo (Ottawa-Rideau):** You've got to give him the answer he wants or he keeps interrupting.

**Mr Tilson:** That's fine, he can interrupt. If he wants to kill time on his—

**The Chair:** Excuse me, I don't think it is an appropriate time for debate and questions. Surely that's in clause-by-clause.

**Mr Marchese:** Mr Chair, if you don't mind—

**The Chair:** Excuse me, Mr Marchese. We are using the time of these good people who have taken—

**Mr Marchese:** No, no, Mr Chair—

**Ms Neely:** That's not fair.

**The Chair:** And that's not fair. If you wish, after they have finished their presentation, we can discuss it as a committee whether or not we're going to permit questions, but first of all let's deal with these good people who have taken the time to come here today, if we may.

**Ms Neely:** Thank you, Mr Chair. Our last presentation, one of the members took 10 minutes of our time. That's not fair.

**The Chair:** That's not fair. Mrs Boyd, you have one minute.

**Mrs Boyd:** First of all, I want to thank you very much for the very clear way in which you put your concerns. I share all the concerns that you've given and I can assure that we'll be advocating very strongly on this committee for some of the changes that you've suggested. I guess it's very important for groups like yours to come forward and talk about the reality of abuse as it occurs, because we seem to be caught in this mythology that all families and all caregivers are always acting in the best interests. We know that's not true and it's important to hear the experience from people like you.

**Ms Neely:** Believe me, I could give horror stories to back up every point that's here.

**Mrs Boyd:** And I too.

**The Chair:** Thank you very much for your thoughtful presentation.

*Interjection.*

**The Chair:** I think it would be appropriate if we get into that at the end of the day, Mr Marchese. You have the opportunity to raise it, rather than taking up the time of our presenters.

**Mr Marchese:** If I can, Mr Chair, since the other group is not yet here, in the past often the opposition members, meaning your colleagues, would ask the parliamentary assistant questions—often—and often we used to answer them. We used to answer the question that was asked, not other questions, as Mr Guzzo was saying. I didn't ask several other points. You'd reflected on paid caregivers as guardians as an answer, and that was all I

was asking. I didn't want long answers or long debates, and it was part of what the deputations have raised. So it's a practice that we have practised in the past.

**The Chair:** Mr Marchese, I haven't ruled on that. I just don't think it's appropriate to take the time of people making submissions for that purpose. At the end of the day, please raise it and we'll discuss it as a committee. We will be here at 5 o'clock today, I'm sure.

**Mr Marchese:** I will raise this another time, because I don't want to take time from the other deputations.

### CAMPAIGN LIFE COALITION ONTARIO

**The Chair:** We have the Campaign Life Coalition, Ms Douglas. Good morning and welcome. You have the floor.

**Ms Mary Ellen Douglas:** Campaign Life Coalition Ontario works at all levels of government to assist legislators in public policy matters that affect society's protection of human life from conception to natural death. We are a grass-roots organization representing thousands of families across the province. We are solely financed by the generosity of our supporters and receive no government or institutional funding.

Thank you very much for this opportunity to address this committee today with our concerns over Bill 19. My name is Mary Ellen Douglas. I am president of Campaign Life Coalition Ontario, as well as national coordinator for Campaign Life Coalition Canada. I am joined by Sabina McLuhan, who is a policy consultant for Campaign Life Coalition.

We support the stated objectives of the government in drafting Bill 19, the Health Care Consent Act. In our view, the legislation enacted in 1992 by the previous government was a classic example of a "nanny state" ideology which led to unwarranted delays for patients seeking treatment and usurped the rights and responsibilities of families to care for their relatives. We welcome this government's understanding that it is a primary right of the family and its responsibility to care for the members when the individual is unable to make medical decisions for himself or herself.

Our concerns over the HCCA centre on five major areas:

(1) A lack of definition of age of consent, which leads to an unacceptable abrogation of parental rights to direct the medical treatment and care given to their minor children.

(2) The problems that can arise with the practical interpretation of advance directives, or power of attorney for personal care documents, which could lead to medical treatment being withdrawn or withheld against a patient's current wishes.

(3) The power given to a substitute decision-maker over revisions to a personal assistance service, which could lead to a withdrawal of nutrition and hydration.

(4) The professional qualifications of those appointed to the Consent and Capacity Board, and the provisions that crucial decisions can be made by a sole member of the board when a vulnerable person has no family or person designated to make decisions on his or her behalf.

(5) The omission of a guarantee for family members of notification and/or participation in hearings before the Consent and Capacity Board.

(1) The age of consent: The HCCA makes no reference anywhere in the draft document to a minimum age for informed consent to medical treatment. It leaves the determination of mental capacity solely in the hands of a health practitioner. This is a curious omission and quite at odds with part I, clause 1(e), which states the purpose of the act to be "to ensure a significant role for supportive family members when a person lacks the capacity to make a decision about a treatment, admission to a care facility or a personal assistance plan."

Parents' rights to direct and control the medical treatment of their minor children are protected under sections 2 and 7 of the Charter of Rights and Freedoms. The right was affirmed by the Supreme Court of Canada in January 1995 in its judgement in *B. v Children's Aid Society of Metropolitan Toronto*. The court held that state intervention that overrides parental decisions on behalf of their minor children is only constitutionally valid if, before the treatment is administered, the state provides an appropriate mechanism for the parents to bring their concerns about a proposed treatment before an impartial body.

The HCCA offers absolutely no protection to parents, or children, from inappropriate actions on the part of a health practitioner. For example, under the HCCA a child could obtain a prescription for contraceptives, an abortion procedure, counselling on sexuality, treatment for a sexually transmitted disease and so on without parental permission or even notification, and solely upon a health practitioner's assessment as to the child's capacity for informed consent.

The situations just described occur all too often in Ontario today. How can a health practitioner—who may be a drop-in clinic physician, a nurse, a psychologist—properly assess the capacity for truly informed consent in a young person whom he or she may never have met before and whose family background is unknown?

Not only is the omission of any protection of parental responsibilities at odds with the intent of the HCCA; it is completely at odds with parental obligations as set out in the provincial Family Law Act. The Family Law Act holds parents financially and morally responsible for the nurture and support of their minor children. This obligation is only terminated when the child reaches 18, or at 16 if the child marries or withdraws from parental care and support.

### 1010

There are, of course, vulnerable young people without supportive families. But the Child and Family Services Act of Ontario exists to act in such situations. The HCCA indicates the explicit presumption that the individual has the capacity to provide informed consent, unless there are reasonable grounds to believe incapacity. The HCCA should also include the explicit presumption that parents have the capacity to direct the medical treatment of their minor children, unless the parents demonstrate their incapacity in this regard.

(2) Advance directives: In 1992, when the Substitute Decisions Act came into force, many Ontarians rushed to sign advance directives and powers of attorney for



personal care for fear that the government would step in should they become incapacitated.

We welcome the government's move to simplify the procedure for validating powers of attorney for personal care and we agree that family members should have the primary right to make medical treatment decisions for relatives incapable of forming their own decisions. But we are concerned that certain underlying assumptions and problems with advance directives have not been examined or addressed.

The current power of attorney for personal care form, issued by the office of the public guardian and trustee in accordance with the Substitute Decisions Act, is available to anyone who wishes to identify a substitute decision-maker for the future. It can be completed quite simply by just naming an attorney, or it can include specific instructions, conditions and restrictions to guide the person appointed.

Many people have great difficulty in clarifying their thinking when they confront the prospect of disability or illness. Some will identify a spouse or close relative, sign the form and leave it at that. Others will say that they do not want heroic treatment or that they do not wish to be kept alive on machines or that they do not want treatment if there is no cure for an underlying disease. Some will not want to discuss the future at all and will place their trust in their appointed attorneys to "do the right thing." Some of us in perfect health today will react casually to a news story of a particularly heart-breaking case by saying, "I would not want to live like that."

Each of these vague statements may well be the only discussion the attorney has to go on. It is all too easy to interpret "I do not want to be kept alive on machines" as a decision to terminate treatment when in fact the machine may only be a temporary measure to assist in healing. "Heroic" treatment may well be invasive surgery but may also carry a high probability of recovery. And those of us healthy today may not realize that it is perfectly possible to live a full and satisfying life with the kind of mental and physical challenges we hope we would never have to experience.

Many people change their minds over the years as they become more familiar with various illnesses and observe others' ability to adapt. Technology will continue to advance and improve treatments. How many will think to check back on their signed advance directives or talk to their appointed attorneys to ensure that their wishes will be respected? We fear that undue emphasis on advance directives and powers of attorney for personal care documents may lead to a misplaced feeling of security and cases of misinterpretation of an individual's latest known wishes.

(3) Personal assistance service: We welcome the HCCA's explicit definition of nutrition as a personal assistance service or a routine activity of living. However, we believe that an amendment to the act is required to ensure that nutrition and hydration can never be withdrawn by a substitute decision-maker. But part IV of the draft HCCA, sections 54 to 60, could be interpreted to allow such an action. In addition, care must be taken to ensure that the provision of nutrition and hydration is always defined as a service and never as medical treat-

ment, as, for example, when food and water are provided intravenously or by a gastronomy tube.

It is important to note that there is only one legitimate circumstance under which nutrition may be withdrawn, and that is when death is truly imminent and the patient is no longer able to assimilate food.

Campaign Life Coalition is actively involved in monitoring proposed legislation which would legalize euthanasia in Ontario. Withholding or withdrawing nutrition and hydration from a terminally or chronically ill patient, or one who is comatose or in a persistent vegetative state, is euthanasia. A patient whose food and water is withdrawn does not die from underlying disease or condition; death results from starvation. This must never be permitted.

This government has a duty to ensure that the 1996 Health Care Consent Act does not provide a legislative loophole through which euthanasia will be permitted.

Public debate in Canada has not yet reached a level where there is consensus to legalize euthanasia, either at the federal or provincial level. In June 1995, the Senate of Canada concluded its lengthy public hearings on the issue and issued a series of recommendations for legislative initiatives. The Senate committee recommended that all forms of euthanasia remain a criminal offence, suggesting only that the Criminal Code could be amended to allow for less severe penalties for those convicted of performing or assisting a death by euthanasia. The federal government has not yet proposed any legislation in this area.

Medically vulnerable people will not be protected from death by euthanasia under the HCCA. It is not sufficient to assume that current medical ethical guidelines will safeguard patients in decisions regarding withholding or withdrawing treatment. As we discussed earlier, many substitute decision-makers will be relying on vaguely worded instructions in advance directives or on casual conversations that took place earlier and under different circumstances. There are health practitioners and many lay people who believe that severely disabled people are an economic drain on the system. There are distressing cases where people can live for many years in a type of twilight zone. These cases cause what one medical ethicist has termed the "worried well" to consider such patients as "better off dead." Good public policy protects the vulnerable from such prejudice and fear.

(4) Appointments to the Consent and Capacity Board: The draft legislation for Bill 19 places a great deal of power in the hands of the Consent and Capacity Board in cases where the individual requests a review of the finding of incapacity to reach informed consent for treatment. It also allows a health practitioner to apply to the board for review if he or she thinks that a substitute decision-maker who gave or refused consent did not follow the rules for substitute decisions.

Should the review confirm incapacity, members of the board have the power to appoint substitute decision-makers and to overrule decisions made on behalf of an incapable person, should they find an earlier decision inappropriate. The board may sit alone or in panels of three to five members to hear particular applications. In view of the power given to this board to make life-and-

death decisions for vulnerable people, it is alarming that the draft of Bill 19 offers no regulation or guidelines for professional qualifications of board members. Appointments to the board are to be made by the Lieutenant Governor in Council. There is absolutely no assurance for the public that those appointed will have the skill and background needed to protect those most in need.

(5) No provision for family input in board hearings: Subsection 30(1) of the HCCA specifies, "A person who is the subject of a treatment may apply to the board for a review of a health practitioner's finding that he or she is incapable with respect to the treatment." The only persons entitled to notification of or attendance at such a hearing are the applicant, the health practitioner and any other person the board may specify.

Given that there is no minimum age for capacity specified in the act, it could well be that the applicant would be an adolescent who could, through this procedure, bypass parental notification and consent for medical treatment. It could also be the case that the applicant is a mentally confused adult wishing to bypass family involvement in his or her treatment.

At the very least, the legislation should provide for notice of an application to the board for family involvement so that board members are not passing a judgement in the absence of relevant information as to the person's background and support systems.

1020

#### Recommendations:

(1) Campaign Life Coalition Ontario recommends that the Health Care Consent Act be amended to include a minimum age for capacity to provide informed consent.

(2) Campaign Life Coalition Ontario believes that the public's ignorance of the hazards of advance directives and powers of attorney for personal care warrants immediate action. If such documents are to remain legally valid, we recommend that the government recognize the potential dangers inherent in advance directives and powers of attorney for personal care and take immediate steps to initiate a public education campaign to ensure that those preparing such documents safeguard their rights.

(3) Campaign Life Coalition Ontario recommends that the Health Care Consent Act be amended to ensure that nutrition and hydration never be defined as treatment and thus withheld from patients.

(4) Campaign Life Coalition Ontario recommends that the government clarify the qualifications required for appointees to the Consent and Capacity Board to reassure the public that those appointed will have the necessary professional qualifications and experience.

(5) Campaign Life Coalition Ontario recommends that the Health Care Consent Act be amended to give the family of minor children or mentally incapable adults a guarantee of notification of and participation in the hearings before the Consent and Capacity Board.

**The Chair:** Thank you, Ms Douglas. We have approximately three minutes for each caucus. Mr Ramsay.

**Mr David Ramsay (Timiskaming):** Thank you, Ms Douglas, for your presentation. I'd like to limit my remarks to the area of age of consent. I noticed your first recommendation is that there be a minimum age for

capacity to provide informed consent. I was wondering, do you have an age in mind?

**Ms Sabina McLuhan:** Yes. We'd very much like to see it become 18, in line with the Family Law Act, which also allows children between 16 and 18 who have either married or left their parents' care and control their own autonomy. But we like to keep things simple, and it seems to us that if parents are financially and morally responsible for the children up to age 18, then they should be involved in these kinds of decisions.

**Mr Ramsay:** I agree with you that it may be simple, but it may not be realistic. The job that I have as a legislator is to try to balance different belief systems that are out there in society with reality, to come up with law that tries to strike a balance. It really concerns me when you're saying a child could obtain a prescription, for instance, to treat sexually transmitted disease. I have two daughters who are now past their teen years, and I'll say unfortunately many of our teenagers are sexually active at I think too young an age, but that is the reality of society. This is a sensitive area within a family, for sure. I certainly would want to feel confident that if for some reason my daughter, who is sexually active, felt she couldn't come to her mother and father, and maybe she had a sexually transmitted disease, she would have the sense of confidence and freedom that she could seek treatment and not put her life in jeopardy. This would be a big concern for me as a parent. It's why I can't really agree with your recommendation.

**Ms McLuhan:** I understand what you're saying, but I think we have to presume that parents are the people who are primarily the most important people to care for their children, much more than any well-meaning doctor or social worker or whoever. I think we have to leave the presumption that parents care. If you have a situation such as you've described, then I think every care should be given between the doctor and the social worker to advise the child to talk to her parents. I think we have to start bringing back, especially in the minds of young people, that parents are not ogres. They may be disappointed in your behaviour, but very few of them abandon them totally.

While we allow these kinds of things to happen, that for this certain disease you don't have to notify, or that or this, you really put a wedge in there in the family unit. We recognize there are families that really don't care, sadly, about their children and we believe that the system does have a mechanism to help those children in the absence of the love and care of their families, but on the whole we believe the family unit should become first.

**Mrs Boyd:** I think we would all like to believe and like to presume that parents care for their children, but the reality that we see in terms of abuse of children, in terms of what happens to children in their families, doesn't carry that through. One out of four girls and one out of seven boys are sexually or physically abused before they're age 18, primarily by family members, and we cannot make the assumption that they are always going to act in the right interests. So the law tries to strike a balance to protect those who can't count on that kind of support, and those who can will come.



Those of us who have children who trust us know that indeed we get consulted all the time about what they need to do in terms of their health care. Those of us who are fortunate enough to have those families mustn't assume that that norm applies elsewhere. We have lots of statistical evidence to show that that's not the case.

I'm very interested in your recommendation around an education component, around explaining to people how important it is that if they're going to give advance direction, they understand what that means. I think that's very important too and I agree with the concerns that you've expressed about people rather casually giving instructions, not understanding what that means, not being precise enough about what that means.

I think that has been a concern all the way through with substitute decision-making. It's something that not just governments need to undertake. I think faith communities that have strong views around this need to be undertaking that as part of their responsibility to their congregants, and that those who are involved in certain health care advocacy groups, for example in the AIDS movement or the MS movement, any of those ones where we have a course of a disease and people know what outcomes might be, have a real obligation to help people to understand what they're doing and what it means when they make that directive. I would be very supportive of your recommendation on that and certainly think that's something we ought to do.

Nutrition and hydration are concerns of mine because I know that nutrition and hydration are withdrawn, and very often withdrawn without any explicit permission, and that really worries me. I wonder, though, if your recommendation that it never be withdrawn is very realistic. Can you imagine cases where it really ought to be looked at as a treatment? You talk about gastronomy tubes and so on. Can you imagine occasions when we would not want that kind of blanket prohibition on the withdrawal of nutrition and hydration?

**Ms McLuhan:** Not in the research I've done. The research I've done indicates that the only ethical withdrawal is at the imminent point of death, maybe within hours. We're not even talking days here, but hours, where the body's metabolism can no longer take the food and in fact it is painful. That is why we explicitly refer to that.

Other than that, food and nutrition are always what we used to call normal nursing care. We get into distinctions when we look at how it's provided. If you're eating a sandwich, that's one thing, but if my grandmother is being fed through a tube, that's called artificial nutrition. However, there's nothing artificial about the nutrition; it's the mechanism. If a baby is drinking from a bottle, that is artificial nutrition. Would we withdraw that bottle from the child on the grounds that this is an artificial means of supplying the food?

I don't think it should ever be considered an acceptable thing to withdraw from a patient because, quite literally, when a patient has the food withdrawn, it is usually withdrawn because the patient isn't dying fast enough. There are cases in Great Britain—the Tony Bland case; there have been cases in the United States—Paul Brophy, Christine Bussalichi and others. The only reason the court ordered removal of hydration and nutrition was because these people were not dying fast enough. I don't see that.

1030

**Mrs Johns:** Thank you very much for your presentation. I get a sense that we could talk to you for a long time about what's in this presentation.

I wanted to just talk for a minute about the advance directives. I'm sure that you have considered this and I just wanted to get your recommendations on this. In subsection 4(3) we talk about advance directives and we say, at that particular point, that if the person who has become incapable because of any number of reasons expressed some interest or some desires—"wishes" I think would be the best word—of how things should happen as he became sicker, they had to be taken into effect. So even though they have an advance directive and then later on they say, "Well, Jeez, I wouldn't want to die that way," and they make some wish and they make it to their substitute decision-maker or to anyone, does that not alleviate some of the concerns you have with the advance directives?

**Ms Douglas:** I can speak to this personally because I recently lost my mother and when we arrived at the hospital, I was dealing with this directly. What I noticed was that the medical profession, because of the act without the amendments that we're suggesting, there was so much pressure on the doctors in the legal aspect that they didn't seem capable any more of making intelligent medical decisions, decisions that doctors would know and act on.

They were asking questions like, "What did your mother say at this time?" As we said in here, I know at one time my mother said, when watching a TV program, "It would be terrible to be in this condition," and yet she was quite aware that God was calling her towards the end of her life. So they were saying: "We don't know. Do we revive or don't we revive?" and it was a very difficult situation for the family, because they weren't taking into account anything we were saying or how we knew our mother to feel; it was what she said at a given time. I think the pressure on the medical community, because of the legal aspect, sort of robbed them a bit of their ability to make an intelligent decision. They weren't really listening to the family. They were trying to guess what the person had said at some point in her life.

**Mrs Johns:** All right. Maybe that's something we have to pound out, but in the act it is saying that later wishes expressed have to be considered. I think that may be something that we should send over to the CPSO or someone to make sure that people are aware of that.

**Ms McLuhan:** It still doesn't help the concern that people will make very vague statements.

**Mrs Johns:** Yes, but you have an intent if you're the substitute decision-maker for your mother. If my mother watching a TV show said that, but all her life acted on a different statement, I'm certainly not going to say, "By the way, she was watching the FBI and said, 'I wouldn't want to die like that.'" I think we have to give people more faith in the fact that the substitute decision-maker in most cases knows what they want, can consider their wishes and put priority to the wishes that those people had.

**Ms Douglas:** But I think the education of the public in general to know the impact of making this decision, the education component there is really important.

**Mrs Johns:** A quick question about euthanasia.

**The Chair:** I'm sorry. Your time is up, Mrs Johns. I apologize.

Thank you, Ms Douglas, Ms McLuhan, for attending before us and for your submission.

**Ms Douglas:** Thank you very much for your time. We appreciate it.

**Ms McLuhan:** Thank you very much for your time.

**Mrs Johns:** That was quick.

**The Chair:** I know. They're all quick around here.

#### CANADIAN MENTAL HEALTH ASSOCIATION, ONTARIO DIVISION

**The Chair:** Next is the Canadian Mental Health Association. Mr John Kelly is the president. Welcome, Mr Kelly.

**Mr Hugh Tapping:** Mr Kelly is ill and is not here. Our apologies. I'm Hugh Tapping. I am a volunteer with the Canadian Mental Health Association, Ontario division. Beside me is Ruth Stoddart. She is an employee and she will be giving you John's address.

**The Chair:** Thank you. If you would proceed.

**Ms Ruth Stoddart:** Mr Chair and members of the committee, as Hugh had said, our president, John Kelly, was unable to be with us this morning. I am an employee of the Canadian Mental Health Association, and my title actually is manager of policy, planning and development. I'd just like to tell the committee a bit about our organization first.

The Canadian Mental Health Association, or the CMHA, Ontario division, is an incorporated, registered, non-profit charity, first chartered in 1952. We have approximately 4,000 volunteers active in direct board and committee service through our 36 branches in the province. Ontario division and branch services and programs are funded through government grants, local United Ways and some supplementary fund-raising activities.

The CMHA has always devoted considerable time to ensuring that government policies, practices and legislation promote the human and legal rights of people with mental illness. For the past 10 years we've consistently called for the establishment of a non-legal advocacy system for vulnerable people.

Our organization contributed to the development of the O'Sullivan report on advocacy in 1987 called *You've Got a Friend*; the Fram report on substitute decision-making in 1988; the Graham report on mental health reform in Ontario, also in 1988; and the Weissstut report on mental competency in 1990. We also made a presentation to this standing committee in 1992 with the original Bills 74, 108, 109 and 110, the advocacy, consent and substitute decisions legislation.

CMHA, Ontario division, has been a member of the Ontario Advocacy Coalition as well for the past five years. We're also represented on the Ministry of the Attorney General's interim advisory committee on substitute decisions legislation and the family and service provider advisory committee, which was established under the Advocacy Act.

We believe that Bill 19, which proposes the repeal of the Advocacy Act and amendment of the Substitute

Decisions Act, Consent to Treatment Act and Mental Health Act among others, requires the attention of every person in the province, because the passage of this bill will affect the exercise of everyone's basic rights.

Now I'd like to turn things over to Hugh Tapping, who will talk to you about the Advocacy Act repeal.

**Mr Tapping:** As one of Canada's oldest charities, we have endeavoured to be polite and to work in partnership with many people in the field, including government. When an organization expresses concern, as you will see in our presentation, it's an understatement. This organization has worked for a long time to see Father Sean O'Sullivan's report come to some fruition. Some people, like myself, have volunteered in this field for so long that I was doing it for a decade before I found out it was advocacy that I've enjoyed.

We recognize that the government is moving to cut expenses. The repeal of the Advocacy Act was right in the government's election document, and the people have spoken. But people still need some things which we call rights advice. There's a strange notion around that you can have a right but not know it and therefore someone's content; it won't be the person who doesn't know about their rights. Individuals need help. You have heard and you will hear very many touching stories. I know lots myself. We will have time for questions.

Systemic advocacy is also essential. It's a funny term, that one; I'm not comfortable with it myself. But what it talks about is, it's not enough to just look after this poor, helpless person and that needy, deserving soul; there are problems that go beyond the individual. Some of them are sociology, some of them are literally the training that people pay for in our universities.

There need to be independent advocates. I'm a volunteer. I come and go. I can't keep it up. The field in itself can be pretty heartbreaking, and people leave for that reason. Volunteers like me, sorry, we're not good enough because we're not permanent. We come and go, and by the time we've learned how to do it well, we've had enough, thank you. Independent advocates are sometimes needed because some people, through no fault of their own, need help getting their desires, their wishes in their lives delivered to them.

As the CMHA, we were very clear that we did not want to get some government money to provide advocacy services. We don't want to put our employees in a potential conflict-of-interest situation. We can acknowledge that, like everyone else, we're not perfect, and sometimes those good intentions that our employees and our volunteers have—well, I think we all know what road is paved with good intentions. We wouldn't want to have people trying to serve two masters.

#### 1040

It should be centralized in some way. Having a whole bunch of people out there in different towns and so on, with no way of learning from each other, seems like a waste of time and money both. People need training. As I said, a lot of people who do this do it out of the goodness of their hearts or because they have a concern. But it isn't easy sitting in a place like this, with those cameras on me. I think it's called "a learned behaviour."



Apparently, you can actually get training in how to be in front of a camera and not feel the way I do right now.

The other point I wanted to make is that there do need to be people locally. Having some office in Toronto with a 1-800 number is not going to help someone in a boarding-house outside the city boundaries of Thunder Bay. I'm going to turn it back over to Ruth with some of our specific concerns. She's a lawyer, so she can tell you about this legislation in some detail.

**Ms Stoddart:** I would like to address our concerns, particularly about the amendments to the Substitute Decisions Act and the Consent to Treatment Act and the Mental Health Act. Most of them are outlined in detail in the submission you have, but I'd just like to highlight some of the ones that we feel are the most important. Unfortunately, some of this gets a bit technical just because of the changes to the legislation.

Some of the concerns we have under the Substitute Decisions Act, in fact most of the concerns, have to do with the removal of any sort of rights advice or advocacy for people who are having powers of attorney activated. One of the first has to do with guardianship of property. Under section 16 of the Substitute Decisions Act, some changes have been proposed which would omit the present requirements for an assessor to explain the purpose of an assessment. It would also omit the requirement for an advocate to explain what would happen to a person if he was found incapable of making decisions. It also would omit the ability of a person being assessed to refuse guardianship.

Instead what is to happen under the new legislation is that the public guardian and trustee will inform the person that the PGT has become the statutory guardian of property and that the person is able to appeal that finding to the new Consent and Capacity Board. What could happen under these amendments, then, is that a person who is thought to be unable to manage property could be found incapable and wouldn't be able to terminate any guardianship without making a motion to court.

Our organization is concerned that people who are indeed quite capable of managing their property might be unable to understand the consequences of a finding of incapacity and also might be unable to understand how to appeal a finding of incapacity. The result of these amendments to the Substitute Decisions Act, we fear, is that the public guardian and trustee, rather than becoming a last resort, could end up becoming the statutory guardian of property for a large number of people.

One of our other concerns with proposed amendments to the Substitute Decisions Act is under the existing section 24. Right now, this provision says that people who provide care services to incapable people cannot be their guardians of property. The amendments to this section would allow caregivers to become guardians of property for incapable people if no one else was found who was willing and able to act.

Our organization's concern, again, as Hugh has stated, is a conflict-of-interest problem arising. If a service provider is providing services to that person, we would question how they could advocate for them as well, particularly if that advocacy involved acting against the wishes of the person's employer.

One of our other concerns is with respect to powers of attorney for personal care. Under the existing section 46 of the Substitute Decisions Act, amendments will remove the word "advocacy." This again is similar to the powers of attorney for property, where a person providing advocacy services could conceivably, under this amendment, be allowed to be that person's attorney for personal care. Again, this would raise questions about conflict-of-interest situations.

One of the prime concerns of our organization was the changes to section 50 of the existing Substitute Decisions Act. This section has been referred to as the Ulysses clause for a number of years. A lot of organizations that work with people with mental illnesses asked to have this section included in the original legislation. What has happened with the amendments to section 50 is that any provisions for rights advice when section 50 is invoked have now disappeared. The person who is granted the power of attorney can no longer revoke the power of attorney, as they earlier could, or refuse its registration.

These provisions were initially in the legislation so that people's rights weren't removed and they weren't deprived of liberty. If these amendments come into force under section 50, the CMHA fears that powers of attorney for personal care under this section could be very much open to abuse, because the person who would be subject to the power of attorney couldn't object to the activation of it, would be unable to seek a review of a finding of incapacity and could potentially be detained against their will, under sections 49 through 51, for up to six months. What happens under these sections is that an assessment of the person who is found incapable can only take place every six months if the attorney is willing to let that happen. So conceivably, a person detained under section 50 could end up being detained for up to six months and not being allowed to make their decisions.

Two of the other provisions of the Substitute Decisions Act we're very concerned about, which I think this committee has heard about already, are the proposed changes to section 66, which delete the prohibition against the use of electroshock as aversive conditioning. Our organization is aware that as far as we know, electroshock as aversive conditioning is only being used right now in one institution in the province, but we still do not believe that it should be allowed to be given to anyone without their consent, and we're also quite concerned that once this provision is removed from the Substitute Decisions Act, this so-called treatment could be used in many more cases.

Finally, under the Substitute Decisions Act, again under section 66, the existing legislation requires various conditions before a guardian is permitted to use restraint on an incapable person. In addition, any use of restraint has to be consistent with a guardianship plan. This second part, the consistency with a guardianship plan, is now to be removed from the legislation. In institutional settings, certainly, there are some controls or should be some controls over the use of restraints. We're very concerned, however, in the boarding-house situation or home care situations, who will monitor guardians and how any unsuitable use of restraints will be controlled.



I'm mindful of the time here. I'll skip to the Consent to Treatment Act amendments.

The Canadian Mental Health Association has three primary concerns about the Consent to Treatment Act. The first one we believe probably could be corrected by more precise drafting. It's the new section 11 of the Health Care Consent Act, which allows variations in treatment without the practitioner obtaining a new consent. There is a part of this section that could be read as permitting a person to be moved to a different place for the treatment, provided the treatment was continued.

We're concerned that in extreme cases a person in a nursing home or some sort of paid care setting, if their money ran out or their finances, they had problems, a person, as long as the treatment was continuing—for instance, the doctor was still seeing them once a week—could be moved to some sort of unregulated boarding-home without their consent, with the treatment being continued.

1050

Our main concern is that the new section 16 of the health care consent legislation, which was section 9 of the Consent to Treatment Act, no longer requires rights advice to be given to a person found incapable of consenting to treatment. What will happen under the new section 16 is that the person found incapable no longer has to be given rights advice. This would mean that substitute consent could be given to a treatment without notifying the person of any finding of incapacity along with various other conditions.

We would question, if a person or a substitute doesn't have to be given any information about a finding of incapacity being made, how they're to know that this finding has been made and how they're to know how it could be reviewed. Again, we'd suggest that some sort of rights advice provision be put back into the legislation as exists under section 9.

I'll go, finally, to the amendments to the Mental Health Act. We have two main concerns here: First of all, the change to the current Mental Health Act definition of rights adviser. Right now, rights advice in psychiatric facilities, in the provincial psychiatric hospitals, is provided by the Psychiatric Patient Advocate Office/Advocacy Commission—it was in transition. The amendments to section 81 of the Mental Health Act will permit facilities to designate and regulate who will be rights advisers. Our concern is that independent rights advice continue to be provided to people in psychiatric facilities, and our fear is the conflict-of-interest situation which could arise if employees of psychiatric facilities are the persons providing rights advice.

Finally, amendments to section 36.2 of the Mental Health Act. This section currently permits a patient in a psychiatric facility to approve that a board-appointed representative is going to act in various situations for them. This representative is the person who is able to allow disclosure or access to medical records. The changes proposed to this section of the legislation basically allow the release of medical records if the patient "does not object." It's been changed from a very active approval process to a passive no-objection process. We're concerned that if the representative doesn't have

the patient's best interests in mind, there could be a serious problem with confidentiality of medical records.

In conclusion, I'd just like to say that, as Hugh has mentioned, we've long been concerned about independent advocacy services and rights advice being provided to vulnerable people in this province. We would urge the government to reconsider the effects on vulnerable people of the removal of rights advice and advocacy provisions from the legislation. Thank you.

**The Vice-Chair (Mr Ron Johnson):** We're going to move on to some questions now. Each caucus has got about two minutes, that's all, and we'll start with the third party.

**Mrs Boyd:** Given the concerns—and I think all committee members will want to read very carefully your whole presentation because it was very well reasoned—would you anticipate there would be many charter challenges to this legislation, particularly under section 7, but possibly under section 12 as well, given the kinds of issues that you've raised around restraint, around detention, around that sort of issue?

**Mr Tapping:** If history was to be our guide, virtually every legislative change in this field in 10 years has been sure to lead to the sky falling. It hasn't yet happened. I recall the final proclamation of long-past subsections of the Mental Health Act which were going to lead to charter challenges and a wonderful job creation program for the law society. It never happened. Usually these things are human things. They tend to get resolved before the specific wording of whatever legislation gets passed. So no, historically, if that's any guide, it's not going to happen.

**Mrs Boyd:** So you're hoping that the changes will occur so that in fact we have legislation that is as charter-proof as it's possible to get.

**Mr Tapping:** The charter-proof isn't my perspective. My perspective is that the charter of rights tells me I have some rights and I want to have those rights here today and elsewhere tomorrow.

**Mrs Boyd:** I understand that, but your lawyer for your association has clearly said there are problems with this legislation that may in fact interfere with the charter rights of individuals.

**Mr Tapping:** It would be a lot easier to not pass legislation that violates the charter of rights and then have to go through all the rigmarole of changing that legislation. We aren't that good at fund-raising to be able to do that. My understanding is it costs in excess of \$50,000 to just make application to begin the process, so obviously, let's make legal laws.

**Mrs Boyd:** On both sides it costs.

**The Vice-Chair:** I'm sorry, Mr Marchese. We're going to have to move on. On the government side I've got three speakers: Clement, Parker and Johns. You've got two minutes, and I'll let Mr Clement go first.

**Mr Clement:** I'll defer to Mr Parker and then pick up if we've got time.

**Mr Parker:** Thank you very much for appearing before us today and bringing us your concerns. We appreciate the concerns you've articulated. Frankly, I think many of the concerns you've raised are already addressed in the legislation that we are putting forward,



perhaps not in those places where you were looking for it, but it's there. What I want to do now is just invite you to meet with us at another time. This isn't the forum in the two minutes that I've got, but I would like to get together with you and we can review the legislation in detail and show you where the concerns you have raised are already addressed.

**Mr Marchese:** Tell us. Tell us all. We don't know.

**Mr Parker:** Well, I'll give you a couple of examples right now, and if you're happy I'll take up some time on that. At the bottom of page 4 you indicate that you're concerned that in order to overturn a finding of incapacity someone has to go chasing off to a court to do that. If you have a look at page 30 of the bill, if you've got it with you, in section 54, which amends section 78 of the existing legislation, subsection (2) of section 78—what I'm referring you to here actually is page 9 and that is paragraph 4 under section 20 of the bill. That indicates that to overturn a finding of incapacity the assessor is capable of doing that. It's only if the assessor fails to find capacity that there is a right to appeal to the court. But the assessor can overturn the finding of incapacity. You don't have to go to a court to have the finding of incapacity overturned.

The other point I want to address—

**The Vice-Chair:** Mr Parker, I'm going to have to stop you there, sorry.

**Mr Parker:** Well, I gave you the reference and—

**The Vice-Chair:** We're going to move on to the Liberal caucus now. You have two minutes, Mrs Caplan.

**Mrs Caplan:** Your organization, the Canadian Mental Health Association, Ontario division, has been long respected as an important organization with a very significant amount of expertise as well as an interest in fighting for the rights of people who suffer from mental illness and mental disease. Were you consulted by the Ministry of Health prior to the tabling of this legislation so you could assist them in the framing of some of the significant changes in the Consent to Treatment Act?

**Ms Stoddart:** No.

**Mr Tapping:** We recognized that the government is moving with some dispatch.

**Mrs Caplan:** You were not consulted?

**Mr Tapping:** That's a long way to say no.

**Mrs Caplan:** Okay. You've raised—

**Mr Tapping:** As I said, we do strive to be polite, Ms Caplan.

**Mrs Caplan:** Yes, thank you. The minister—I won't go into that.

You've raised a new issue that I'd like to draw to everyone's attention, and that is the issue of passive consent. In other words, if you don't object you are deemed to say it's all right. There are a couple of cases where this is a change in this legislation and it's not only over the release of information, it's also on the appointment of a representative, and that's new.

Could you just expand a little further on your concern, because I share that concern about why that was done. Was there a problem with the old Mental Health Act that it required explicit consent where a person was capable? Now this is a significant change.

**Ms Stoddart:** You're referring to appointment of a representative under the Mental Health Act. I think the concern is that under the existing provisions of the Mental Health Act the patient could approve who the board designated as the person's representative. Again, I don't have any experience as to what goes on inside the psychiatric facility, but would assume that the patient is asked. You know, the board has appointed this person.

The problem we see with the amendments to the legislation is that the board could appoint a representative and that representative could then act as long as the patient didn't object, as opposed to being asked to approve. It's the change from one to the other. I guess, in the extreme, someone who maybe even was non-verbal or whatever could basically be taken as they didn't say no.

**Mrs Caplan:** I think that's a new and important point. I hope the Information and Privacy Commissioner's recommendations will help address that, because I think that's one case where people should be able to consent if they're capable to do so.

**The Vice-Chair:** Mrs Caplan, we're out of time. I'm sorry, we're going to have to stop you there. Mr Tapping and Ms Stoddart, I want to thank you on behalf of the committee for your presentation. You had some very thoughtful ideas in there and I'm sure we'll have a very close look at it.

The next name on the list for presentation is Mr David Cooper. I don't see him and I don't think the clerk has found him either.

1100

PETER SIMONSEN

**The Vice-Chair:** We'll move on to Peter Simonsen. Hello, Mr Simonsen.

**Mr Peter Simonsen:** Hello, everybody. Thank you for the opportunity to talk to you.

**The Vice-Chair:** You'll have 30 minutes, and if you want to leave some time for questions, that will have to be included in the half-hour.

**Mr Simonsen:** I have only two pages. I read this ad in the paper and I thought it was important that you hear from someone on the back concessions. I'm not used to making this kind of presentation, so I trust you will forgive me if I stray a little widely on the subject.

The three acts that Bill 19 proposes to repeal or revise were, I believe, subject to amendments in 1995. At that time I attended a presentation by a government lawyer at the retirement home where my father-in-law resides. It was my opinion then, as now, that the government was intruding far too much into the private affairs of individuals and families, that it created more bureaucracy and paperwork, and that it set up new opportunities for disputes and costly litigation. The laws and the changes may have been well motivated, but as you know, the road to a certain hot place is paved with good intentions.

At the presentation I talked to the old folks and found that many of them, as credulous good citizens, had gone to their lawyers to get the new papers filled out. The lawyers' fees had ranged from \$30 to \$400. I suggested to the government lawyer that the whole thing was a scam to make money for lawyers. She allowed that some lawyers were making "a good thing out of it."

These laws were made in 1992, changed in 1995 and are now subject to change again. A lot of confusion is being created, a lot of expense for taxpayers and individuals. How can you make long-term plans in this area and in any other area of life and business when the rules are changed constantly? Why can we not have simple, straightforward laws so that we know where we stand, and then make it difficult to change them?

The élite and the bureaucracy seem to be of the opinion that us ordinary folks don't know what is best for us and how to handle our affairs, and that they do. Personally, I find this kind of government paternalism offensive.

For a thousand years, we lived by the common law, which was based on tradition and common sense. It was usually just and it served us well. Over the last generation or so, the common law has been pushed aside by administrative laws that often violate both common law and common sense.

A wise man once said, "The best laws are those with which earlier laws are repealed." So let us go back to the common law and common sense. I would advise this committee to draft an omnibus bill that abolishes all laws that have been passed in the last 50 years, perhaps 100, and then disband itself. I guarantee you we would have a better, more prosperous country.

The laws are being created by an élite that often stands to benefit from them. We have many monopoly laws that benefit well-financed lobbies at the expense of the rest of society. The country and its legal system should belong to the ordinary people who in the final analysis pay the bills through their labour. Why are you sitting up there and I down here? It should be the reverse. It's a question of power.

Now let me describe how common sense worked within my own family. My grandmother died about 10 years ago. She managed her 98th birthday and her daughter's silver wedding anniversary party, and then she decided that she had had enough. She went to bed, wouldn't get up, refused food. She was not hauled off to hospital, she was not fed through tubes. She wanted to die and was allowed to. Two months later, she died at home in her little apartment in the old folks' home.

I suspect that in this country, in the absence of written instructions, both the administrator of the home and the doctor could be sued, perhaps even criminally charged for not intervening. That is nuts.

My grandmother had no will. My brother and my cousin obtained a homemade power of attorney from the two daughters. They took them to the probate office where the clerk looked up the names and then issued a form with a stamp on it that authorized them to look after grandmother's estate. They cashed in her investment certificates, paid the bills and divided the rest among the two heirs. Then they made up a statement of dispositions and certified that, to the best of their knowledge, the bills were paid. Then they were discharged from their fiduciary duties. It took a month.

My mother died a year ago. She had been in a nursing home for less than a year. She had Alzheimer's. Near the end, she could not recognize her own kids. She developed

two problems: She could not swallow, and also something internal that would have required surgery. The nurse that my brother usually talked to asked him what they should do. "Well," said my brother, "I guess the best thing you can do for her is to keep her as comfortable as possible." My mother stayed in bed and three weeks later she was dead.

When the four of us kids arrived for the funeral, three of us signed a simple homemade power of attorney to the brother who lived nearby. We verbally told him to keep a sum, because he had been taking care of things over the years, to buy something nice for his wife who had been wonderful to our mother, and to divide the rest among the grandkids. Six weeks later, he faxed me a copy of the statement. The cost was \$25 for the stamp at the probate office and some value added tax on the funeral arrangements. It took my brother 24 hours to obtain a probate certificate; I am told that it takes six months in Ontario. Also, a percentage of the estate has to be paid to the province up front. We ought to ask ourselves how we can justify inconveniencing our citizens like that.

About 90 years ago, a Danish prime minister travelled to France. He was so impressed with the tall, well-dressed gendarmes he saw there that he decided Denmark should have gendarmes. A writer at the time tells about one of these tall specimens with shiny boots and polished brass buttons riding on a white stallion into a small village in Jutland. The villagers had gathered on the main street in anticipation. As he neared a large mud puddle, the townsfolk sicked their yappy dogs on him, with the result that he fell off the horse and landed in the mud to a roar of laughter. He got back on the horse and rode out of town the way he came and was never seen again. Thus ended an experiment with authoritarianism.

Thanks to such incidents, I grew up in a basically self-policed society. As a teenager and as a young man, I could go about my daily life of work and play without ever having anything to do with cops or lawyers or judges. There were no enforcers whose career advancement depended on writing tickets or winning in court. So I say to the authoritarians, take your intrusive laws, get on your horses, ride out of town and don't come back.

**The Chair:** Thank you, sir. The government, Mr Tilson.

**Mr Tilson:** I hope you don't think of all members of the government in that tone. Perhaps I can just respond with some philosophy on the topic of too much government. That's what we've been trying to do with this bill.

**Mr Simonsen:** I support 100% the government in cutting expenses. As far as I'm concerned, you're not doing it fast enough.

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**Mr Tilson:** Maybe I should stop at that stage. I think I'm going to call it quits. I think that's the philosophy of our party, that we do have too many laws. We are too intrusive into the private lives of individuals.

**Mr Simonsen:** Right on.

**Mr Tilson:** I listen to stories particularly of our parents and grandparents when families looked after each other. Times have changed. There's no question times have changed. In the past, women didn't work. Most



people work, men and women, or at least try to work. So there are times when I suppose, if there is no one else, if there is no member of the family, if there are no friends, or if there is abuse, then we believe the state should become involved, and that's the simple message this bill is giving.

**Mr Simonsen:** Wouldn't the common law cover that?

**Mr Tilson:** Well, it has.

**Mr Simonsen:** How did we deal with it 50 years ago?

**Mr Tilson:** I think we all have to acknowledge that there is abuse; there are situations when families simply don't care. My friends, particularly from the New Democratic Party, will tell us that. They'll be itching to tell you in fact that there are examples where there is abuse, and that's true. I agree with them. There will always be abuse; and I think no matter what our political stripe is, we must endeavour to deal with that. I think that's where we differ with our two philosophies. I don't know where the Liberals stand, but certainly with our two philosophies we just wish to solve it in a different way. Thank you for your comments.

**Mr Simonsen:** Can I just say, on the qualifications for nursing home staff and similar staff, the one overriding qualification should be compassion, and almost everything pales in comparison. Sure, you need nursing skills—but compassion. If they don't have that, they shouldn't be working there.

**The Chair:** The loyal opposition. Mrs Caplan.

**Mrs Caplan:** I'd like to thank you for your presentation. One of the concerns that I have about this legislation is that if you are in a situation where you are found to be incompetent and it's decided by a health practitioner that someone else is going to be asked to make the decisions on your behalf, in fact, quite contrary to I think everything that most of us believe in, they don't have to tell you. Are you aware of that?

**Mr Simonsen:** I would depend on my wife or my kids to make those decisions. I realize that perhaps there are some families where this would not work. The subject of euthanasia was raised. Now, we never know what we would do in a desperate situation, but I would think that if I was very sick with cancer, in a great deal of pain and knew that I had only a few months to live, that's an option I would choose for myself possibly. I think if I did, it would not be anybody else's business.

**Mrs Caplan:** That subject of course is something that's within federal jurisdiction and the federal Criminal Code, and euthanasia is not legal in Canada. The story that you tell about your family actually is a very lovely story. I was touched by it and I wished all families were as loving and generous with each other as the story that you told. Unfortunately, that's not the reality. We know of child abuse, we know of elder abuse and we know of vulnerable people who have been abused even in institutions. That's been the history, unfortunately, of too many vulnerable people. So while the ideal is something we all aspire to, I believe that we have an obligation as a society, that if there is something we can do to offer those who are in a vulnerable situation some protection, we have a right and an obligation to do that.

**Mr Simonsen:** In the 1960s we started passing a whole bunch of laws supposedly to protect people, but

governments don't protect me now. Caveat emptor doesn't apply any more, and there is more cheating, much more than then. In those days, you only had to worry about certain used car dealers, but today everybody is out to scam everybody.

**Mrs Boyd:** I think Mrs Caplan is right: You're very fortunate in terms of the family experience that you talk about, and naturally, speaking out of that experience, you have views about what the norm is.

The reality is that it doesn't matter what party is in power; parties don't go into government and make legislation unless they have a ground on which need has been established. We're heard here at this committee about the number of studies that were done around the vulnerabilities of people, the tragedies that had occurred. What this government, the previous government, and previous governments before that have tried to do is to have the kinds of protections there when things go wrong, and I think that's very important.

I would take issue with my friend Mr Tilson and remind him that women have always worked. It's only recently we've been paid for our work when it's outside the home. Mr Grandmaître and I really wanted to remind you of that. But you're very right that the changes in our family structures and in the way in which we interact are a very important part of the vulnerability that we face. All of us used to in most cases enjoy an extended family situation where there were others available to assist and to help and in fact to prevent abuse by one person of another. As we've changed our family structure and moved more and more into a nuclear family structure where people move around a lot, those natural protections of a knowing and loving community and an extended family that was available to monitor situations are not there for many families.

That's one of the problems that people who are in legislatures face: How do we look at what we know from evidence—from criminal evidence, from social evidence, from all of that—how do we look at those abuses and try to find ways to prevent them from happening in the first place by giving the maximum amount of choice to the individuals themselves? That's the whole purpose behind this kind of legislation, to try and give the individual who is most affected an opportunity to make choices and the right to make those choices in an informed way, and that's the purpose. If we go wrong in that, if we're not doing that in the right way, then obviously it's the job of the Legislature to look at changes that might need to be made.

**Mr Simonsen:** I agree that there is a lot of stress on families, particularly economically nowadays, and I think a large part of it is political decisions that have been made over the years. When I was young I could buy a house for twice my income, one week's pay paid the mortgage, and mother stayed home and raised the kids and raised them well. Today that can't be done because of the HUDAC legislation and the monopoly that has created, and the planning boards, all the planning bureaucracy which makes a house twice as expensive as it needs to be. Get rid of that stuff, I'll build you a house for half the price, and the families that are now in public housing

could be living in their own homes and the mothers that wanted to could stay home and take care of the kids.

**Mr Marchese:** Mr Cooper, I wanted to say that you've given us your opinion; I wanted to give you mine as well. Mr Tilson talks about too much government and too many laws and you agreed with that. Mr Tilson doesn't say that they passed Bill 26 most recently, which is one of the most intrusive of bills that I have yet seen around here. So it seems interesting that when it's convenient to the government, they pass laws that are very intrusive. When it's not convenient to them, they say, "We pass too many laws."

The other point is too much government, and you said you agree with him in that they are not going far enough and fast enough. I can't see a government could be going faster and in a much more mulish way. If they went any faster it would be a disaster. We're already in a big problem, because you see, as this government's cutting back, it's devastating families who are not working, and once people are not working, they are destroyed.

With respect to this particular bill, Mr Cooper—

**Mrs Boyd:** It's not Mr Cooper; it's Mr Simonsen.

**Mr Marchese:** Oh, sorry; 11 o'clock. Mr Simonsen.

With respect to this particular bill, what we try to do—generally, I think everybody tries to do this—is not to say that families are good or that they're bad, but rather to admit and acknowledge that in some instances some individuals out there don't have families, so they need protection. Someone has to protect them.

In some instances, as we have seen from a number of people if you've been watching the proceedings here, there have been many, many abuses by caregivers, by people who presumably love them. So the point is, how do the laws protect them? It's not that we want to say the families are bad. We don't want to say that they are. We want to acknowledge that some are not. So the point is, how do you build into those laws protections when there are abuses? These are the questions we're raising and the questions that a number of deputations have raised, which we hope the government members are going to listen to. 1120

**Mr Simonsen:** Well, I think some of those abuses are criminal in nature and are properly covered under the common law.

I would like to respond to Bill 26. It is probably an authoritarian piece of legislation, which I don't like. However, I think in the present circumstances it is necessary because we have to cut and it seems that everybody thinks they're too important to be cut. You know, the police are too important, the teachers are too important, the bureaucrats are too important, the firemen are too important, and the three senior judges give a bad example by saying that they are too important to be cut. It can all be cut.

**Mr Marchese:** Mr Simonsen, I don't see how we could justify certain laws—

**Mr Simonsen:** May I just carry my train of thought through here? One thing the government has to do which I have not seen yet is create an atmosphere in which jobs will be created, in which I can again become an employer, which I used to be. I have not seen that yet.

**Mr Marchese:** Don't worry, it's coming.

**Mr Simonsen:** The risks for me as an employer are simply too great. I saw one young fellow who was starting in the building business, as I did 30 years ago, and he had an argument with a health and safety inspector, so they went over his place with a fine-tooth comb and he was fined \$47,000. He lost his house and his business, and the inspectors and the prosecutors took a round, shook hands, "Nice job," you know? It made you sick. I cannot afford to take a risk. If I hire a young fellow, and no matter how well I instruct him, if something goes wrong it can cost me 500 grand just like that. I cannot work under those circumstances.

**Mr Marchese:** Mr Simonsen, I hope this new program serves you well. Thank you.

**Mr Simonsen:** Well, I'm looking forward to that.

**The Chair:** Thank you very much, sir.

**Mr Simonsen:** Thank you for listening to me, even though I may be a little argumentative.

**The Chair:** Thank you for taking the trouble to attend before us. It's much appreciated.

**Mr Simonsen:** I hope I didn't offend anybody.

**Interjection:** Not at all.

DAVID COOPER

**The Chair:** The next person on the agenda is Mr David Cooper. Welcome. You have half an hour, which would include any questions you might wish to answer, and the floor is yours.

**Mr David Cooper:** I'd first like to thank the committee for allowing me to appear here and also for its patience in extending to me an extra 20 minutes, given that I was late, and reversing positions with the previous speaker. I have not compiled a formal written statement as such to complement my oral presentation. At this time I simply wish to discuss my concerns and to present a few valid points that are certainly sentient to my personal beliefs.

This is relevant. I apologize. Although I have not made provisions at this time to view any portion of this video, as it is not particularly sentient to my presentation, I have simply produced it as physical evidence of the fact that I want you to know it is actually in existence.

This video contains a Rogers Community 10 production of myself that I produced for a local cable television outlet outlining how I feel that psychologically damaged individuals should have the prerogative of state- and physician-assisted suicide if they so wish. I am a great proponent of rights for the mentally ill, even to the extent of this extreme measure.

I would also like to add at this time that I am against the dropping of the Advocacy Act. I thought it was a very important piece of legislation. I was under the impression that it was designed for no other reason than to be for the welfare of individuals with severe psychological problems, such as myself.

I've had psychological problems for most of my life. I am 30 years old. I haven't had a job in five years. When I was 16 I had to live in a mental health centre. I lived there for two years and then afterwards I had to live on the street. For the last 10 years I've had to get what-



ever job and whatever place to live I could. As we all know, the Consent to Treatment Act and the Advocacy Act did not exist in those times. It would not really have been relevant to my situation anyway. I was simply expected to be completely self-sufficient and self-reliant.

That is my primary point here today: that there are so many people who are resigned and are required because of their personal circumstances to be their own advocates, to be completely self-sufficient. I cannot see that dropping the Advocacy Act and following through with other measures, other what seem at a casual glance to be hopelessly bureaucratic measures to reform other acts in relation to mental health, could really be considered practical less than four years before the next millennium. Psychiatry is not supposed to be in its infancy any more. We are supposed to be much more enlightened as a society, and yet some of these measures just seem to be a fallacy geared towards a system that was already abandoned nearly 20 years ago.

If mental health centres were able to guarantee that never again were there going to be sterilizations and lobotomies and shock therapy and other invasive forms of therapy, and if individuals who were required to live in such institutions could expect to be able to live in clean, quiet, enlightened, liberal, pleasant domiciles where they could reasonably expect to be able to have a comfortable existence, then some of these measures would probably be valid. But as it is, given that we've cut back on housing programs, we've cut back on any of a number of other initiatives, people who have psychological problems have their backs against the wall and this is just creating a downward spiral for them. That's why I felt compelled to come today to speak about this.

At the time that the family services act was being designed, I was living in a mental health centre. The people who ran this organization had 24-hour access to me, and in spite of that, no one could be bothered to bring to my attention the fact that these hearings were taking place and that perhaps I would be entitled to give a deposition. The only means I had at my disposal of articulating any grievance about the mental health centre in which I lived was to write a letter to my member of Parliament, as if they would even have known what to do with it. In later years, I became actually a constituent of Mr Marchese. I can only assume that through an unfortunate oversight Mr Marchese did not apprise me of the hearings at that time regarding the Consent to Treatment Act and Advocacy Act that were taking place at the time at which I was his constituent.

On and on through the years I've had to be alone. I don't have anyone to be reliant upon. I guess I feel like I've missed out, I've really sort of missed the boat, and I can certainly appreciate the statements made by the previous witness about how difficult it is to subsist in this society. Bill 19 may not be draconian in nature, but it certainly is I think rather naïve not to believe that simply bureaucratizing further an already marginalized portion of our society is really quite unfair. We have the Mental Health Act. It doesn't seem ever to have occurred to anyone just simply to alter the Mental Health Act to provide the personal liberation that should be available to people with mental health problems in conjunction with what the Canadian Constitution is supposed to stand for.

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Every time someone like me gets confronted with an accusation of being psychologically disturbed, it means getting taken to the hospital by the police, who are basically acting as agents of the Ministry of the Attorney General; it means being viewed by doctors who are under the Ministry of Health, following guidelines that coincidentally also happen to be under the Ministry of Health. But all this bureaucratization and decentralization is not really conducive to providing good mental health care. That is further exacerbated if you happen to be a child, because then you've got three different ministries. As the members of the committee I'm sure are aware, all aspects of children's mental health care are administered by the Ministry of Community and Social Services. So it's just a hopelessly bureaucratic situation, and from the casual glance that I have had of the new bill, it does not reconcile all these problems in terms of really spelling out in clear detail how we can ensure that the welfare of these marginalized individuals can be safeguarded.

To further elaborate on what I've been trying to say, as we all know, four homeless people have died on the streets in the last month. I think it just shows that people don't want to take advantage of what's out there because the so-called safety net of our society never really was adequate. People would rather take their chances on the street than worry about being in an unsafe hostel or the hostile environment of a mental health centre.

In my life I've gone from being perceived as a childhood prefect who spent five years receiving piano instruction at the Royal Conservatory of Music and six years singing in one of the most conspicuous and well-known children's church choirs in the city to living in a children's mental health centre as a teenager, to living on the street, to having jobs guarding warehouses and shopping centres as a security guard, to spending years being marginalized as an adult victim of mental health problems. My life as a psychologically damaged individual who is also a law-abiding citizen is difficult enough without having to worry about fashionable whims of society on the one hand, with political correctness and natural law and all that sort of thing, and on the other hand reforming and getting back to basics and all those sorts of things.

We've gone through so many changes as a society. I guess I feel like I'm caught in the middle, like I'm one of these typical generation Xers. If I'd been my age 60 years ago, I could have died in war or in an industrial accident or of an urban plague or I could have died in prison. Ten years ago, as someone who was born out of wedlock, I could have been aborted. As it is now, as a 30-year-old male in today's society unfolding as it is, with the problems that I have, I feel like I don't know that I belong anywhere. It doesn't seem like society seems to be able to make up its mind about where I belong. I know that's the idea of the hearings that we're having today. I'm just saying I don't believe that what is being proposed here today is really the answer.

One other thing I would like to point out is that if you had been truly interested in trying to reach other consumer-survivors such as myself, the best way to have done so would have been to advertise on buses and

subways and in bus shelters. To my knowledge, the only advertising that was done about these hearings was in the newspaper, and a great number of mentally ill people do not read the newspaper either because they find it disturbing or because they simply can't afford it.

If we can find some way to reconcile the Mental Health Act, perhaps revise that and bring it in line with what the Constitution represents and make it constitutional, then I suspect that maybe some of these suggestions proposed here today would be more valid. But as it is, I don't feel that I'm prepared to endorse them or be party to them as a member of society who is duly affected by the changes being proposed.

At this time I don't feel I have anything left to add to the personal presentation I prepared, so I could take questions.

**Mrs Caplan:** Thank you very much for coming. I think it's important for the committee to hear from people who've had experience, and clearly you understand the workings of the Mental Health Act. One of the questions I believe it's important that if you are declared to be incompetent and incapable of making your own decisions, you have a right to be told that. This bill removes all rights advice but it also removes the obligation from anyone who has made that judgement, any professional, to tell you that someone else is going to be making decisions for you. You didn't comment on that specifically in your presentation.

**Mr Cooper:** I am prepared with a comment to the fact that you've brought it to my attention. I do agree that people need to be apprised of their condition. When I was 16, I was diagnosed as having schizophrenia. Had I known that was the diagnosis that had been reached and what it meant, I think I probably would have taken my chances with living on the street at that point instead of allowing myself to become psychiatrized, only to wind up on the street years later. I really do believe it is important to know what your diagnosis is, how it will affect you and how you will be perceived by others as a result of that.

**Mrs Caplan:** There is one other thing that I'd like to just tell you and any of my constituents who are watching, that they should not expect that I can contact each one of them personally to let them know about hearings. Members don't have sufficient resources to do that. So whether it's Mr Marchese or Mr Tilson or Mrs Caplan—

**Mr Cooper:** I just mean that I actually visited Mr Marchese in his office.

**Mrs Caplan:** I'm not defending him. I'm just saying it's not a reasonable expectation. Maybe I am defending him, because your comment was that you would expect your member to let you know.

**Mr Cooper:** I just mean—

**Mrs Caplan:** You were there. I see.

**Mr Cooper:** At that time I had a visit with him at that office coincidental to the hearings specifically related to those concerns. As I was saying, through what appears to be an unfortunate oversight, I was not apprised of the fact that hearings related to the very thing I'd articulated concerns on were actually taking place.

**Mrs Caplan:** I just wanted you to be aware that in my riding there are 70,000 people.

**Mr Cooper:** Certainly I understand, yes.

**Mrs Caplan:** I can't possibly afford to contact each household to let them know about hearings like this. The costs of government would increase. I'm not suggesting I should be able to have those resources. We rely on the clerk's office to post notices in the newspapers, but we also rely on the media to let you know through radio and so forth that hearings are taking place. People can contact the committee and if there's a space available they can come, like you have, or they can write to the committee or phone a member, as I read into the record earlier today, with something they wanted to say. I would encourage people to feel that they can come forward. It is unfortunate that we can't let them know individually, but we just can't afford to do that.

**Mr Cooper:** One of the other problems is that people feel so hopelessly marginalized by the government that they might not even feel safe being in these kinds of surroundings. As restraining and unpleasant though it may be, it's more a matter of the fact that this is not something most people with psychological problems are accustomed to, and only through my personal and professional experiences am I equipped to do so.

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**Mrs Caplan:** You've set a good example. Thank you for coming.

**Mr Cooper:** I would be willing to entertain other questions at this time.

**The Chair:** Sure. Mr Marchese. We take them in order, Mr Cooper.

**Mr Marchese:** Mr Cooper, we appreciate your presentation. With respect to your meeting with me and whatever discussion we might have had, I don't quite recall what we had agreed to do, but if there was an oversight, this is a good opportunity to apologize for that.

With respect to your comments on the Advocacy Act, I'm one of those who finds that what this government has done, repealed the Advocacy Act, to be a reprehensible act. I believe they're doing a great deal of damage by repealing the act altogether. There are ways to amend it, ways to make it less expensive, if that's what they thought it was, but to completely eliminate it isn't a responsible act.

The Advocacy Commission would exercise its power for advocacy services, which is to say that it was there to help individual vulnerable persons to express and act on their wishes. That's what the commission was there to do, to help vulnerable people, and it's gone now. Rights advisers are gone. It assumes that everybody out there, caregivers and families, are all good, we don't have to worry about it, everybody can go back home now, government is less intrusive, they say, so everything is solved.

**Mr Cooper:** I'm sorry to interject, but for the record I agree with all of Mr Marchese's comments up to this point. Please continue. I apologize.

**Mr Marchese:** The point I make is that once they get rid of this commission, we have a problem. When they get rid of the rights advisers we have a problem, because who do vulnerable people turn to for assistance? That's the point. You said you were against the repeal of the Advocacy Act and you didn't elaborate. I wanted to know



from you why you thought the repeal of the act was a problem.

**Mr Cooper:** Actually, I quite agree with your comments. I do feel that it is naïve at best and irresponsible and reprehensible at worst. I believe it was a necessary piece of legislation because so often the only resources that people with psychological problems have are each other, and this means that they cannot act on each other's behalf. They have nothing with which to act. They are powerless against families.

I heard in comments made to the previous witness that supposedly the new changes that are being proposed are a way of admitting that there are certain drawbacks in families in the state in which society is today. However, repealing the Advocacy Act is not any sort of an appropriate way with which to deal with that reality. We needed the Advocacy Act. It was really necessary.

I don't understand why people don't understand that, apart from the fact that there are so few psychiatric survivors who have had the opportunity to ascend to either public life or to a position of public responsibility as those gathered here today have been able to. Being in government constitutes a tremendous responsibility and a tremendous opportunity. I think that sometimes those who are in power really forget that and forget what it can really mean for individuals like myself whom society just doesn't seem to be able to make up its mind about.

**Mr Parker:** Thank you very much for appearing before us today and for your very eloquent remarks before us. I'd like to pick up on just two points that have emerged in this discussion. One is your comment regarding publication of notice of the hearings themselves. I take very much to heart your point that the notice of these hearings is limited in its circulation. As we've already discussed, that's a question of limited resources and that's a reality that faces us—

**Mr Cooper:** But it would only cost as much to have advertised with Trans Ad and Mediacom as it would have been to have published advertising in the newspapers.

**Mr Parker:** What I want to say to you specifically in response to your remarks is that I take your comments very much to heart and I am going to look into ways of increasing the profile of these committee hearings in my own riding through the mechanisms that are available to me. I'm grateful to you for raising that as an issue.

The other point I'd like to delve into a little bit more deeply, a point of substance, is one that was raised earlier by Mrs Caplan concerning notification or disclosure to the patient when a finding of incompetence has been made. Right now the bill is silent on that point.

You speak to the professionals; they will tell us, and they have told us, that their own professional ethics, their own code of conduct guides them in these matters, and where it is appropriate and possible, such disclosure is made. Where it is not possible or where it is not appropriate they have other ways of dealing with these things. Overall the suggestion there is that we leave it to the people who are trained in these areas to use their professional trained judgement to guide them as to how to handle matters of that sort.

In your own case you said that had you been advised of the finding made concerning you at the time when it

was made, it would have affected your behaviour, and would have led you to a choice to live on the streets.

**Mr Cooper:** Well, given that—

**Mr Parker:** That's one of the concerns that's brought to us by the professionals. If this disclosure is made under the wrong circumstances or in the wrong way—

**Mr Cooper:** I don't think—

**Mr Parker:** Let me finish the question and then I'll leave it to you. If it's put to the patient in the wrong way then it will have a detrimental effect on the treatment of the patient. We as legislators have to reconcile those two points of view, and I'd like your guidance on that because it's a question that we're all grappling with.

**Mr Cooper:** Well, sir, the point I was attempting to make is not that it would have affected my behaviour, but that I would have made a conscious decision about my life, about what to do, because I was not welcome to live at home when I was 19. My parents ejected me from my home when I was 19 due to comments ranging from the fact that they were not comfortable with my homosexuality and my behavioural problems, to the fact that I was constantly a presence around the home and didn't go out and did not appear to do anything constructive. That was the basis upon which my parents ejected me from my home. It had nothing to do with truancy, or with criminal behaviour, or drug problems or anything like that. My mother herself admitted at the time that she had some personal problems which she thought at some point she would examine doing something about. She did not follow through with that at any point between 1982 and 1989, by which point all of these events that affected me had already unfolded and taken place.

That's what I'm getting at. If I'd known I was going to eventually just have to be completely independent and self-reliant, not only because of my familial situation but because of the way in which the children's mental health system and adult mental health system are not reconciled and joined together, then, as I said, I would simply have made a conscious decision to leave home and to try and make it on my own three years earlier than I did, instead of allowing myself to become, as I said earlier, psychiatrized.

Doctors don't have all the answers. I feel that psychiatry has become a modern-day panacea for the manner in which we deal with our personal issues. As you can see, there are quite a number of breakdowns. Psychiatrists and people who run mental health centres claim that they want all these relevant decisions to be left to them, and we've seen in abhorrent examples like Mount Cashel, at the Queen Street Mental Health Centre, and with the life and work of Dr Ewan Cameron and with any of a number of abhorrent examples, right down to much more neutral and benign examples of the sort of neglect that I was subject to, that just leaving it up to the professionals is not really the answer.

I had to live in what was basically an unheated shack for about two months during the winter of 1993 at the mental health centre that I used to live at. Just a few months prior to that, I believe it was between July and September 1993—or 1983. I would like to recant what I just said; I am referring here to the year 1983. Between July and September 1983, half of the people, which was



eight other residents of the mental health centre where I was living at the time, chose to run away from the centre, to physically leave the premises without permission because they were so demoralized, and no investigation of any sort was made at the time to determine why morale was so low among the residents.

As we've seen from what has been unfolding, commonplace all over North America in the way in which we've been examining the past histories of orphanages and mental health centres, we can't just simply place it in the hands of doctors and caregivers.

**The Chair:** Thank you, Mr Cooper. It's very valuable for the committee to get a survivor's perspective. Thank you for coming forth to provide that to us.

**Mr Cooper:** Thank you. Are there any further questions before I go? No? Okay. Thank you very much for allowing me to speak. I hope you will be willing to take most of what I said to heart, because I know I certainly do.

1150

**The Chair:** There's one matter before we—perhaps two. One of the individuals, Ms Hall, who was to make a presentation yesterday and unfortunately was not able to, cannot attend except for today at 5:30. We're going till 5:30 and the question is, I want your guidance as to whether or not we will permit her to speak at 5:30, which means we'll go till 6.

**Mr Tilson:** Mr Chair, I personally have another commitment that I made as a result of the previous agenda, so I won't be able to be here at 5:30.

**The Chair:** That's one individual. I'm still—

**Interjection:** I'll be here.

**Interjection:** I can be here.

**The Chair:** Okay. It's through no fault of hers that she's lost her place, and I think it's great that we can accommodate her.

Now we can deal with Mr Marchese. I just want to make my position clear. I attempt to be fair to all caucuses. I attempt to allocate the time fairly to all caucuses, and I must thank you in advance because your cooperation has made my job easy.

I am concerned. I feel I have another obligation; that is, to provide the time allotted to our guests. I know that wasn't your intention, Mr Marchese. One-minute questions I'm not concerned about, but a debate that detracts from their time I am concerned about, and I'd like your guidance as a committee on that.

**Mr Marchese:** Just to say that you've been a very fair Chair all along, so that's not the issue. I had asked an earlier question to the parliamentary assistant based on what the Toronto Mayor's Committee on Aging had said. One of the concerns that they raised, that Ms Neely raised, was that to make paid caregivers guardians and to give them priority as caregivers over the public guardian in trust as a court-appointed guardian was a problem, that it leaves itself open to a great deal of possible abuse, particularly given that there are no rights advisers any longer, that there is no requirement to produce financial reports any longer and that there's an elimination of restrictions on the use of restraints. So it's a problem.

All I asked the parliamentary assistant was a question. I didn't want to argue with him; I don't want to argue

with him now. Have you thought about what people have been saying with respect to this? Have you thought of either eliminating or amending? That's all I ask. All I want from him is a quick answer. If he doesn't have it now, he'll give it to me later, another time, because I will ask it again. That's all.

**Mr Tilson:** I guess I can briefly make a comment that we believe the court should have the discretion to appoint service providers where appropriate. We are confident that a judge, a court, can decide what is best for an individual in the circumstances you described and address any potential conflicts.

**Mr Marchese:** We'll come back to that. Perhaps Ms Boyd has something, but I'll come back to it another time. That's fine. I just wanted to know your answer and that gives me a fairly good sense of where your thought is at the moment.

**The Chair:** I'm pleased to see you're all so amiable.

**Mr Tilson:** I'm open to debate this at clause-by-clause, and if you have suggestions to put forward we'll be pleased to entertain them. You asked what our position is at this particular point in time, without hearing further comments from delegations that are coming forward. We still have two more weeks of hearings. There may be some comments that may be made, and if not, if some of the delegations do not make presentations on this particular issue and you wish to at the appropriate time, we'd be pleased to entertain any suggestions that you have to improve the legislation, as usual.

**Mrs Boyd:** Since we have a couple of minutes before 12 o'clock, on another matter, a number of the delegates have talked about the issue of volunteerism, certainly the government side have talked about volunteer advocates and the adequacy or lack of adequacy of volunteer advocates in the absence of the Advocacy Commission.

I'm a little puzzled that we weren't all given the report the Advocacy Commission wrote in 1995 on volunteer advocates. It's a discussion paper. It has a number of models around volunteer advocacy possibilities. I wonder if I could table it with the committee and ask that copies be provided to everybody. I think it's important that we know this work has already been done and it's not as though the Advocacy Commission was in any way suggesting that volunteer advocates were not appropriate. I think it's really important.

I'm not sure that the Advocacy Commission didn't add this to their package that they gave us, but it hasn't been called to the attention of members, and I think it's really important for us to look at, since we're hearing again and again from delegates that if we're not going to have the Advocacy Commission, then which of these other models could we have? We may want to set aside a little bit of time for us to talk about some of the suggestions in here, since it seems to be something that we're all very interested in having a bit more detail about and certainly the people from the Advocacy Commission didn't have time to talk to us about the models they had looked at.

**Mr Tilson:** Just a comment on that. You're suggesting that we set aside a time frame to discuss what goes on, what has been reported in that report. We'll be reading that and we'll be reviewing it. Mr Reville has come to this committee and has expressed his views; the Advo-



cacy Commission representatives have come and expressed their views; we're going to have—if we haven't, members of the committee will have an opportunity to read that, will have an opportunity at clause-by-clause debate, but I don't really think that to take away the rights of other people to come to this committee to set aside a specific time to debate that particular issue. I think our obligation at this point is to hear from as many people as we can—I doubt if we'll be able to hear everyone, but as many people as we can—and then, at the appropriate time, to debate that very issue. I'm sure, knowing what your views are and Mr Marchese's views, that we'll have some very stimulating debate.

**Mrs Boyd:** I was by no means suggesting that we would want to take away from the right of people to testify in front of the committee.

**The Chair:** No, I think that was a misnomer.

We'll recess until 1:30.

*The committee recessed from 1200 to 1335.*

#### ONTARIO PSYCHIATRIC ASSOCIATION

**The Chair:** We have members from all the caucuses here. Can we proceed with the afternoon session of the standing committee on administration of justice. Our first submission will be from the Ontario Psychiatric Association, Dr Brian Hoffman and Dr Lucien Faucher.

**Mrs Johns:** Do we have a paper on this?

**Dr Lucien Faucher:** No.

**Mrs Johns:** Okay, thank you.

**The Chair:** You may proceed.

**Dr Faucher:** I'm here as president of the Ontario Psychiatric Association and my colleague Brian Hoffman is chairman of our legislative review committee. I should tell you a little bit about who we are in getting started and why we're interested in this legislation.

Essentially, as you know, psychiatrists are all physicians. We're all specialists, interested particularly in the treatment of mental illness. We're interested in the broad range of all the problems of mental health and mental illness. So we're here as physicians, as psychiatrists and we're as an association as well because we represent all the psychiatrists in Ontario.

There are roughly about 2,000 psychiatrists across Ontario, many of whom work in hospitals, many of whom work in their private offices. Particularly in hospitals we inevitably become involved in issues of capacity. I think it's a very natural process for our colleagues in general practice or in surgery or in other specialties to turn to us when they have a patient who's disturbed and they're not quite sure what to think of them. It's very much part of our training and part of our day-to-day work to be able to help them out with this. So we're very directly involved as physicians in the application and the day-to-day application of these laws and in helping out our colleagues.

Actually we're here, by and large, to support the new legislation. We're quite happy with the tenor of the legislation, with the changes that have been made, by and large. I'll speak about that in a broad sense and then my colleague Dr Hoffman will go into more detail.

I particularly like the stated purpose of the changes in the sense that it purports to help patients move through

the health care system with fewer barriers to care, that it would be workable and have fiscal responsibility and would give more responsibility to family members to make decisions. That's very easy to support as an association of psychiatrists, so we're here particularly to support the legislation.

I'd like to mention something that always bothered me about the existing legislation in the consent to treatment, and it's a subtlety, but I guess psychiatrists are used to subtleties. There was a kind of underlying assumption that physicians were to be suspected, that physicians may not have the patient's best interests in mind. The whole tenor of the legislation, of the laws was almost to protect patients from physicians. That wasn't said, but it was sort of felt as an underlying premise. I think that was sad because that's not the case. We're very interested in our patients' welfare. We're very interested in their rights to get timely care and to have access to care. I think that should be said.

Another thing in the existing legislation that seemed a bit along the same lines was the idea that families were perhaps not given the recognition they may deserve, by and large, in wanting what was best for their family members. I think the new legislation has brought that to the fore and corrected that.

The idea of having a presumption of capacity first and foremost is really important. I think it's safe to assume that most of our patients have capacity to consent to treatment, and to start off with that assumption makes sense, and to only rule it out when we have very good reason to do so. This is particularly important with an aging population and issues of aging in which the presumption of capacity will become more and more important.

I mentioned that, like it or not, we're involved in capacity assessments in helping our colleagues out in hospital settings. It's not written into the legislation, but we certainly play a role in that capacity on a day-to-day basis and it may be worth considering the role of psychiatrists in that regard.

I'll turn the podium over to my colleague Dr Hoffman, who has more specific points to make.

**Dr Brian Hoffman:** Thank you for allowing us to present today. Not only am I chair of the legislative review committee of the OPA, but I also run a day treatment unit and community outreach program at Mount Sinai Hospital. My clinical interest is in treating very ill psychiatric patients.

There are tones and implications in the current legislation that made it very difficult for us to treat psychiatric patients. There are some improvements in your proposals that we wish to support. Earlier this week, I spent a couple of days at an inquest in Toronto that you have been following regarding Lonnie Clemens, a young man who died directly resulting from decisions whether he was capable or incapable of consenting to treatment for constipation, in most cases a trivial condition, that within four days became life-threatening and he died.

I urge you to listen very carefully to the recommendations from the coroner's inquest. The timing was brought forward so that their findings from the lay public having looked at the very practical implications in one man's life

could be brought forward to you for your consideration, without your worry of perceived bias either from the advocate side or the professional side. Certainly the jury is going through a complex series of deliberations.

It may be that his death was related to not just the content of the legislation related to capacity and consent but also the process of the legislation. The death occurred within eight weeks of the introduction of the legislation, and to this day, except for a very few academics in the province, very few professionals can remember, repeat, act on the legislation because it's so complex and incomprehensible.

To expect not just our profession but roughly 100,000 professionals in the province to get on top of this over an eight-week period was unrealistic. We had two and a half years to review the legislation, but it wasn't till February, two months before implementation, that we had regulations. Because of the lack of regulations, those of us who belong to professional bodies and are educators were unable to formalize our recommendations to professional groups, not even knowing which professional groups would be involved, what the standards of capacity assessment would be and what the rules regarding other components would be. We were totally paralysed. Even though the leadership understood the legislation, we wouldn't have wanted to mislead our membership in any way. Getting some, what appears to be minor, area wrong just becomes totally confusing to professionals.

Before we touch on the content, you really must carefully consider the process, and in particular, what kind of time line you give us, not just to review your current proposals but to give us time and funding and means to educate after regulations are produced that have a direct bearing on professional actions and judgement.

To be a bit more specific about the content, psychiatrists generally would support the removal of the rigid criteria that exist in regulations, section 4, regarding capacity assessments. The rigid checklist of procedures is not how clinicians think. It's a legal mechanism, but when you study how clinicians think, they think in patterns. They look for connections, not a checklist. When you look at someone and you're wondering whether they're capable or incapable, in 95% of the cases it's quite clear: You've got an Alzheimer's case; you've got someone who's quite capable. In trying to understand the law, they realize, "Gosh, I should have asked these questions." No, because in fact the assessment is based on your total picture, on history, on past psychiatric history, on medical history, on current mental status, on observations of others.

If I tried to get a paper published, and I did, on capacity assessments and I recommended to professionals that they use a checklist only on existing answers and observations, that paper would be, and in fact was, rejected because a clinician quite correctly pointed out, "That's not how clinicians work." In the vast majority of cases, yes, you can do a legal, but when it's complicated, when it's complex and critical, you must consider all areas of information that are available to you over a period of time from all sources to come to a reasonable, reasoned decision. That's exactly what's missing in section 4 in the regulations.

It may be contributing factors to cases such as Lonnie Clemens, when decisions are made very quickly without all available information. In fact, all available sources of information were not elicited, were not sought, even though they were in the same room. To the degree you checklist things, you interfere with the best thinking of experienced clinicians.

The next point I wish to make is to reiterate an old point of the flaws in reasoning when you separate psychiatric patients from the physically ill patients. To develop two different sets of laws is not something that makes any sense in current psychiatric thought, with the qualifications that psychiatrists in this country have, as physicians first, and where patients are usually treated in general hospitals.

### 1350

Three areas where you continue to discriminate against psychiatric patients, perhaps interfering with their treatment and certainly stigmatizing psychiatrists as people not to be trusted and psychiatric units as not to be trusted: First is that you make rights advice mandatory for a psychiatric patient, not for the physically ill, so that if I treat, and I do, a patient with neurosyphilis and brain disease, there's no mandatory rights advice, and I treat that same patient with identical symptoms with schizophrenia, then I must. It makes no sense in clinical practice and it leads you down the garden path that if you have rights advice for psychiatric patients, you should have it for all patients, when in fact I would say that all patients should be treated equally. But why are you setting up practitioners to be seen as untrustworthy and setting up an adversarial system in what should be a therapeutic alliance?

The second is, you block admission to a psychiatric facility, even if it's a general hospital, which can be overruled by a person who's deemed to be incapable, a clear lack of logic, when in fact I could be treating a similar patient with neurosyphilis or brain disease—post-traumatic injuries—and the patient would not be able to thwart their own best treatment as recommended by a professional and approved by a substitute decision-maker, whom you also continue to disallow and disfranchise with your legislation.

Thirdly, the emergency treatment of patients considers severe suffering. You don't define whether that includes mental anguish. There's the danger it would be interpreted as only physical pain and not mental pain. This is not the route that many of the states in the United States have gone, with over 50% of them recognizing mental conditions. You put an emphasis on serious bodily harm and again discriminate against psychiatric illness.

On the more positive front, you have allowed treatment after a capacity review board has determined the person is incapable. Under the current active legislation, we would have had to wait seven days. It makes no sense. You've got a professional who is meeting professional standards, you've got a substitute decision-maker who cares about the patient and who has been screened by the treatment team, you have a Consent and Capacity Review Board which has given an impartial hearing. I am still aware of psychiatric patients who, through appeal mechanisms, have gone six months and more without treat-



ment, sometimes in solitary confinement because they're so dangerous, and these are cases you would know of in the law because they're reported in *Fleming v Reid*. They're bad enough, but to routinely block treatment, even without an appeal, makes no sense after the number of people who have supported the treatment decisions.

One last point I'll make: I don't even know if it would go into legislation, but a flaw concerns the capacity review board, in that they have no funds for education. I've been on the capacity review board for the past eight months. It means that as a hearing member, or before that as a psychiatrist appearing, we never were educated and to this day have never been educated about previous findings. It means every case starts from scratch.

I have been at more than one review board that before we started we knew we had no jurisdiction. It took three hours to convince the applicant's lawyer that that was so. I think it's because of a lack of educational process. That lawyer was told by the chairman, but he wanted to give his argument. If it had been in writing that these cases had determined this process, then I think you would have saved everyone not only the expense but the anger that flowed from that hearing by the applicant, who was not the patient, at his frustration because his lawyer had pressed. He and his daughters were furious at the health care, at lawyers, at government, because of an educational process.

Certainly, as psychiatrists, we would love to have information about what the review boards are doing, what their findings are, and yet Michael Bay tells me there are no funds for education. Something has to be done about that so we don't start from scratch.

Those are a few of our points that I hope you'll take constructively. We do support many of the changes that you have brought about, feeling that they are more supportive of the physician-patient relationship than the previous adversarial system that was being promulgated by the legislation. Thank you. We would now invite any questions that you have.

**The Chair:** Mr Marchese, you have a couple of minutes.

**Mr Marchese:** Thank you for your presentation. I do have a few questions if we have time and if the answers are also brief. With respect to the Advocacy Act and the Advocacy Commission, do you have any comment about that? Because this government has said it's repealed.

**Dr Hoffman:** Do you want to deal with that, Lu? Do you want me to?

**Mr Marchese:** As briefly as you can, just to have a sense.

**Dr Hoffman:** In essence, we saw the powers of the Advocacy Commission as far too broad, far too extensive, perpetuating the adversarial system. I think the government does have now an obligation to protect vulnerable people who are in institutions. It's my understanding that there is legislation in place in terms of the Long-Term Care Act and facilities that will do that. I think that's a better route to go than the broad, sweeping Advocacy Act.

**Mr Marchese:** There's a lot I could say about that but we don't have the time. The Psychiatric Patient Advocate

Office obviously holds a different view, but I can understand where you're coming from.

With respect to rights advice, it makes it mandatory for psychiatric patients that there is rights advice given, and some people think that that's perhaps, if the psychiatric facility is the one that determines who the rights adviser is, a conflict, they argue. It could be a conflict. But you're saying, simply to have patients who are psychiatric patients getting the rights advice creates a problem in terms of the perception that psychiatrists are not to be trusted. Are you saying rights advice should be given to all patients as opposed to singling out mental patients? Is that what I understood you to be saying?

**Dr Hoffman:** I would like to clarify our position on that, and that is, there's been in the legislation a melding of two different processes. One is notification of the finding of incapacity, which I think is a professional task, an ethical duty when we find someone incapable. I think it should be in professional standards because if I have a paranoid patient who's angry, who thinks I'm a member of the FBI, if I then must say, "You are incapable," then he loses control, he loses face, he's embarrassed later, feels badly, and we have trouble forming an alliance. If on the other hand I can show some judgement here and say, "We're having trouble reaching a decision here on what's best. I would like to bring in your father or your wife and bring them into the equation," then it's unlikely we're going to get that escalation of anger that the adversarial system brings in. I think we need some judgement about that and I think the profession could develop that, knowing that the person still has to be told of their rights.

1400

I'm not sure a professional physician—that we know anything about declaring rights. So I think there's a government responsibility to educate people. I think institutions could be made responsible to do that. I don't see a conflict at all. You've got a professional meeting professional standards, you've got a substitute decision-maker who is being screened by the professional who's going to act in some way, you've got another body telling them their rights, and you're going to have a fourth body, in fact, that the person can go to. I think that is more than enough rights and time and effort to be an efficient system.

**Mr Tilson:** Thank you for your comments. I will say, Dr Hoffman, that we have asked for the recommendations and the results of the inquest. I guess it's expected next week or in the next couple of weeks.

**Dr Hoffman:** I think so, yes.

**Mr Tilson:** The committee hopes to be able to review those. I'm sure that it will be very pertinent to our deliberations on Bill 19.

I think we appreciate your acknowledgement of the goals of restoring balance to the situation, taking away the presumption that all health caregivers are suspect. Many people have come to this committee and many people have called us, and that has been the response with respect to the current legislation that exists.

I would like to move away from that into an area that you didn't really talk about, and that has to do with financial incapacity, and talk about the problems that individuals may have; specifically, when I say "financial

problems," financial difficulties, practical problems such as exploitation, failure to provide necessities of life, those sorts of things. I don't think we've really heard too much about that.

**Dr Hoffman:** It's an immense problem in psychiatry. Once there's a dangerousness standard and the person is admitted involuntarily to hospital, it is not much of a problem any longer, because we must go to the public trustee with a finding of incapacity, so that's okay. But both depressed and manic patients who are quite ill and in the community and not needing involuntary hospitalization can in fact literally decimate their financial resources.

I've seen a pharmacist who became paranoid his wife was having an affair. He started sending his money down to the States. He planned to quit his job and move to the States. Trying to find a way to treat this man was absolutely impossible. In fact, this story ends rather sadly with a suicide before he was ever admitted to hospital but after he had shifted money down to the States and lost.

It is a major problem. Psychiatrists have developed some expertise at assessing financial capacity. We do it, but we do it because we're trained in it and because it's expeditious compared to any court thing. So we're pleased with the power to be able to help people in that way, although it's an unusual power to give, since it's not directly related to treatment.

Do you have a more specific question?

**The Chair:** No, I'm sorry, time is up. Mrs Caplan.

**Mrs Caplan:** Very nice to see you here, Dr Hoffman, and welcome, Dr Faucher. You raise a couple of issues, one that's been raised before that I think is particularly important as it relates to the Clemens inquest. The Clemenses are constituents of mine. I have my own views on reading the legislation and I feel that Lonnie should have been treated, especially given his record of incapacity. I want to be on the record as saying that while I had problems with the previous legislation, I felt that was something that was more than unfortunate.

I think this legislation would allow the same thing to happen again, and I would refer you to the definition of treatment where, for the purpose of incapacity, clause 2(1)(g) says, "A treatment that in the circumstances poses little or no risk of harm to the person." While it does refer to "apparent distress" as opposed to "serious," you might get a different response from the attending physician, but if anything this makes it worse because it exempts this, as you described it—and I wrote down your words—trivial procedure from this legislation. I think that's a potentially serious consequence and would ask you to think about that and perhaps suggest an amendment, because while we don't want every low-risk procedure to be captured by this, there's got to be a way to allow this to opt in in those kinds of situations.

The other point I wanted you to speak a little further about: The Consent and Capacity Board has no mandate for education, and this legislation doesn't give them one; therefore, the ministry has no obligation to give them resources for education. If a mandate were given, it wouldn't require an automatic flow of resources, but it would alert everyone to the fact that there is a requirement for education, put an obligation there. While I know some informal things are being done to educate, I'd like

you to speak to that. Do you think this bill should contain a mandate for education of the kind that you mentioned, and education of families and consumers and professionals, about this legislation?

The last point: Was the Ontario Psychiatric Association formally consulted by the minister before this legislation was tabled for first reading? Did you have a chance to meet with him and offer him your advice?

**Dr Faucher:** No, we didn't.

**Mrs Caplan:** No, you didn't. I'm trying to find out who did; that's why I'm asking that question. If you'd like to take the remaining time to address the issues that I've raised, I'd appreciate that.

**Dr Hoffman:** I appreciate your comments about how to address the issue of funding for education, because obviously we must first address the need: Is there a need for education? I would argue very strongly yes, in many different areas, not the least of which practitioners and lawyers who are appearing, but ultimately even review board members such as myself. I view it as one of the most unique boards I've ever sat on, that I have to educate myself.

I understand the issue of which procedures are included under treatment. There's the danger that things that aren't included would be required under common law, and that would certainly create a problem when you're doing, for instance, a rectal examination, as in this case. The plus side—and I'm not quite sure how to get out of it. I suppose if you included it under "treatment" but then excluded it from "consent procedure," trivial procedures, maybe that would be a way of developing it.

What is pleasing about the legislation is something we've argued for a long time: a preamble stating its purpose, that it is not just for rights but for treatment of the incapable person, involving the families in the care. That would directly affect the attitude people bring to such examinations. As Lonnie, where when you come in with a rights attitude towards treatment, then you think legalistically, and if you bring it back towards the middle, hopefully clinicians will think clinically, with a rights component. I really think it's important that we teach clinicians to not think like lawyers. There's a different way of approaching ill people that must be compassionate, caring, think in patterns and not think in checklists. When the going gets rough, you need an expert; yes, he can come in and do some checklist work, but the comprehensive history and mental status is always critical.

**The Chair:** Thank you, Dr Faucher and Dr Hoffman. I've let you go over five minutes. Your submission was very interesting to all members of the committee and we thank you very much.

1410

#### FAMILY MENTAL HEALTH ALLIANCE

**The Chair:** The Family Mental Health Alliance, Mr Errol Young. Welcome, Mr Young.

**Mr Errol Young:** Thank you. It's very good to be here. A few familiar faces, but still a strange environment for me, I must admit. This is Joyce Santamaura. I'm the co-chair, mainly by fact that she didn't want to be, and I apologize—



**Ms Joyce Santamaura:** He's much better.

**Mr Young:**—but she's a stalwart supporter of what the alliance is doing. You see in our submission we've really put this together quickly. This is a work in progress you have before you because we had to try to make some sense out of this, which is the copy of the bill we have.

Plus this is a very difficult time of year for families. You may or may not know, but families with people with mental health problems find the winter solstice challenging, and my family is personally finding it challenging. But in spite of that, we've put this together and we wanted to give you some idea of what the family alliance was and what we're trying to do. You see, we hope to work somewhat on a more political footing—we've just started—than other family organizations have, and we're also trying to coordinate family organizations together. It's a rough road but we're trying to do it.

Because of the mental health reform process, a process which I think has almost unanimous support in theory—whether it has adequate support in funding, we will see in the next few years, but we are also involved in that. A number of us sit on the mental health steering committee, so that's where we have our input, and we sit on it as family members.

Bill 19 offers many problems and challenges to us, of course. First of all, we find it close on the heels of the original bill, very close. In terms of normal bills, the original has had no life at all, and if there were mistakes being made under it, I would agree with the previous speakers that it sounds to me more like process. I'm not blaming, but it sounds to me more like process than details, because we search in this bill for an improvement and we don't see improvements. We see difference and we see some things that are disturbing, a few things that are good. We don't really see overall improvement of what we had before. We actually have people now poring over the 110 pages of the bill and you will be hearing from them in other guises. They will have a lot more knowledge about the bill than I do at this stage, but I'll try to give you at least the point of view that we've come up with.

Let me state how we relate to consent and treatment as family members. Most of our relatives are adults and they end up being children, friends, parents, mates etc in many relations, in any human relationship you can have to the 5% of people who eventually come in contact with the mental health system and the minority who have consent problems. If we're coming from a point of view, it's more in the guise of the old act, not so much the rigidity of the old act, but the old act did respect the fact that our relatives are citizens; they have rights and privileges as citizens. That, to us, is extremely important on many levels.

The doctors who appeared before you talked about that as well, praising the legislation because it gives more recognition and more responsibility to families and it does go into ranking, although that's under the other legislation as well. But you've got to realize that I'm a lot older than my son. I don't know how old you think I am, but I'm a lot older than my son, by some 30 years.

I do intend to die before him, and I'll tell you, he will remain ill. Put the two together. If I'm there, if I'm put forward as the person to look after his rights and privileges, how am I going to do that from the grave? I won't be able to do that. There has to be some systemic way of doing that. The previous legislation did that. This legislation doesn't really do that or doesn't give me pause to think that his rights will be protected in those ways. So that's the stand we're coming from. We really are on the side of consumers in saying they are people, and when you take away their rights, it better be for a good reason; you'd better be able to justify it.

We do know, though, that at some point some of our relatives have rights taken away and need rights taken away for the protection of themselves and others. And we support that, because we see that as an emergency situation naturally growing out of what mental illness does to a person's mind, a person's life, their future. It happens.

As family members, we are called upon to perform functions of attorney, decision-maker—under this act it's going to be rights adviser—and that's usually very appropriate. We assist our relatives in many ways when they're feeling better. We help them financially with housing, medical and vocational advice, transportation etc. So we probably know our relatives better than most. At the same time, as adults, they have the right—and do so in many cases—to restrict information from us, keep information from us. They have that right, and I don't necessarily want to challenge the right, but it does hurt the ability of families to help. So we labour under that, but we also understand it on another level. The bill really can't and doesn't correct this.

I did go on, on page 3, to outline a few areas of the bill where we're not sure about what it means and what's going to happen. I guess another area is, for the bill as a whole, we're not sure how it knits together. We know there's a different philosophical standpoint, but we're not sure how it comes out. Again, you'll hear more on that later.

My section numbers may not be as accurate, but I tried to stick with page numbers. Any time there was a number on a page, I quoted it. I couldn't find the section that was 20 pages earlier.

On page 78—let's see what this deals with. As family members, we trust professionals quite a lot. At the same time, we have been victims of malpractice or dubious practices by practitioners as well on all levels: social workers, psychiatrists, nursing staff. For the most part, 98% of the time, wonderful, but those 2% can do a lot of damage, especially considering the ability to incarcerate, the ability to drug, the ability to take away rights. Those are serious skills that they have.

We see in the bill a reliance on good faith, moving away from liability. This may be normal legislative language, but to us it smells like you're trying to take accountability away from those who are administering sometimes extreme powers. Police as well are included in this. I don't think the bill can do that constitutionally. I think there's a common-law ability to sue if you've been wronged. This legislation might be able to do that, I don't know, but it shouldn't.

I think the doctors who are sitting here should have a legal responsibility. No matter how good-natured they are, no matter how good-intentioned they are, if they actually do harm against the Hippocratic oath, we have to have a right to have some recourse, not only to help the family involved but to say to the doctor: "Oh, I better not do that again. It'll affect my bottom line." Basically in society, I don't know what other recourse there is. We don't believe in corporal punishment or anything like that. That's the only one we have. So to me that is an important area to look at.

Page 54: I think this is exactly the same thing, good faith, just pointing it out again. You use the term "reasonable effort" to find a decision-maker. What's a reasonable effort? A person is brought in by police in handcuffs; they're erratic, they're shouting, they could probably hurt themselves or others. Does "reasonable effort" mean one call down the hallway of a hospital to find out if the relatives are around, or is it one phone call if they happen to know where to phone? You wonder about reasonable effort.

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The reason I'm worried about this is not that we don't want to see doctors perform emergency procedures to protect the immediate health of the person. If you find somebody bleeding on the road, you stop the bleeding, that sort of thing. And I agree with them, it's not much different than regular health care procedures. But there are irreversible procedures, such as ECT, such as psychosurgery, which may not be performed exactly in an emergency situation but stemming from it. We don't want to see those procedures performed without more than just a reasonable effort—with a clear effort, some sort of liability, for the hospital to actually go searching for people and find those people before extreme efforts are taken. We don't really see that in the legislation.

The next page, 49, here we deal with conflict of interest. I know this government doesn't like rights advisers too much and it certainly doesn't want to pay them. Then don't have the institution that's incarcerating our relatives or treating our relatives pay them to come in and give them rights. My family, in dealing with an institution—this was in the early 1980s—had only the institution to find out about the rights. We had to ask. We called up the chief psychiatrist and asked what our rights were, and she told us we didn't have any.

I don't know whether that's true or not even today, but I'm telling you that there are more things going on in the head of the person who works for the institution, like their job, like their promotion, like not making waves, that are realities that can get in the way of the rights. Remember, I'm going back to the beginning. We want the families, but we also want our relatives to have their rights restored as much as possible and as soon as possible. This doesn't do it. So I would like you to remove the ability of the hospital or the institution to appoint a rights adviser—simple as that.

Who would do it? I don't know. Right now there's someone. When my son is in a locked unit, the next person after the psychiatrist who comes in is the rights adviser, and I'm glad they're there. He should be there. Now, if it's a volunteer, that's fine. I don't know who

can do this on a regular basis but a paid person. If you're not going to pay them, then there should be some ability for a hospital to bring in a third party. There has to be some neutral agency looking at this, because we're dealing with human rights.

The next one deals with communication, and I'll just briefly go into that. The multicultural nature of Toronto means that you don't know who's going to walk in the door. We've heard tales of a Somali woman being obviously floridly psychotic, but the first thing they did was take her up and a couple of males stripped her. This was nothing improper. Probably happening to most women it would be disturbing but not bad. It was horrendous to this woman. It changed her life, because she remembers it even though she was psychotic. Culturally, it was totally, totally wrong. There have to be some sort of cultural interpreters there for people, not just language interpreters, when you're dealing with the multicultural.

A public guardian should not be able to delve into the accounts of the people they're trusteeing for services. For legitimate costs, fine, but if every time the family makes a phone call to a trustee, that trustee can charge the patient by the minute, that's ridiculous. We're talking about some of the poorest people, people who have been impoverished by mental illness. Mental illness impoverishes them. Inappropriate—totally inappropriate.

On page 5, you'll see a set of recommendations which I don't recommend. I actually recommend these recommendations. They're slightly different. I told you it's a work in progress. Late last night, I changed some of them. So I'll read through them and then give them to your clerk so they can be redistributed. I'm sorry for that.

Here are the recommendations:

That the act not limit the liability of any professional involved in its administration.

That the province maintain an independent system of rights advisers—that's a wish list—but failing that, it is imperative that there be a mandated body that will provide education to vulnerable persons and their substitute decision-makers on their rights and responsibilities under the legislation.

That any emergency treatment facility be obligated to involve cultural interpreters when dealing with people who cannot communicate their consent in all but the most extreme cases. Again, somebody bleeding on the road, you help them, but once you have breathing room, you delve into it in a culturally sensitive way.

That it be mandated by this act that vulnerable persons be informed of the change of their status prior to any treatment being administered. That's not in the body of my work, but it became clearly apparent.

Let me tell you, my son is right now under whatever the previous bill is. He's in Sunnybrook. The first thing the doctor did was say, "I'm changing your status professionally." Wonderful; I'm glad she did it. She didn't have to. That disturbs me. Unlike the doctors who were here who want freedom from legal restraints—I'm sorry, they have a legal obligation to deal with their power in an appropriate manner and they should learn the checklist. I mean, they're going to make their decision based on their holistic view, the gestalt of the situation. We know



that. They wouldn't go through the checklist unless they did. But you've got to have some sort of legal formality before you take away people's rights.

You mention ECT. Why? It's the only procedure you're mentioning in the document. It seems out of place. It is a very controversial procedure for families and consumers and practitioners. So I suggest you deal with it in a more rational way, in other legislation when you're dealing with all treatments, if you must, but not here; it doesn't make any sense.

The public guardian shouldn't be allowed to make a profit off our family members. I really don't think it is possible.

I thought I was coming here and I didn't have much to say beyond this. I mean, I don't think I have the greatest depth in this act. I tell you, I have not read every word. Listening to the doctors beforehand, if I were a psychiatrist, which I'm not, I would say they look like—and they're good people; I have no doubt about that. But they come to you with sort of a professional paranoia. They're saying, if you have legal constraints around them to protect people's rights: "You don't trust us. Why don't you trust us?" That's one way to look at it, and it's a very paranoid way.

The other way to look at it is asking the doctors, "Where is your accountability?" When you're accountable, when you have an accountability procedure, it not only protects the people you're dealing with—patients and families—it protects the doctors. "Yes, I did this, this and this, according to the rules," whatever rules are there. They don't want rules. They want to do it on their good graces. There have been many horrors done to people by the good graces of the medical profession; we know that. Family intervention, assigning rights, may or may not help in correcting that. Certainly liability helps in the long term in correcting that—not on an individual basis—and that shouldn't be taken away.

I was very disturbed by their attitudes, coming up here and whining, "Why don't you trust us?" I do trust them in many ways, but I certainly want an eye looking over them, and a powerful eye. Also—and they raised the issue for me; I didn't see it in the act—why don't capacity review boards have some sort of history and education presented to the members and those undergoing the process? There they made legitimate sense and I support them completely in that.

I'm ready for any questions you have, but be kind to me, like I say.

**The Chair:** Mr Tilson, you have four minutes.

**Mr Tilson:** Just with respect to fees, one of the questions you mentioned about fees, I can understand certainly you made the comment that in some situations one's estate can be depleted. That is a serious concern. I can only assure you that the Attorney General hasn't made any new decisions with respect to new fees that are going to be required with respect to this legislation. However, there are a number of services that cost a lot of money—mediation, appointing private guardians—that have a significant cost. An application to a court for guardianship normally costs in the range of \$3,000. Mediation costs \$100 per hour, depending what you're getting into, of course, in the private sector.

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The question is, how much should the taxpayer subsidize these proceedings? It's a clear situation that if one's estate doesn't have the money, the state will have to come in, but clearly if people are able to pay for certain services, it's just like anything else, whether you're competent, incompetent, any sorts of services. In situations to make the blanket statement that taxpayers should subsidize these services, I don't know whether I necessarily agree with you or I've misunderstood you. I agree with you in part, but I don't know whether I'd go for the blanket statement that the public guardian and trustee should not charge any fees. I don't know whether you can comment on that.

**Mr Young:** Yes. The first thing that comes to mind is, should only the rich be able to afford these services? Because it's very expensive. You say, "Well, the government will step in when we've impoverished the account of the person enough." So you can say the person's allowed to have \$1,000 in their bank account. They have \$700. We're going to go through it, go through it, go through, go through, and they get out of the hospital and they've got \$1,000 in there and they've got two months' rent due. What are you doing to that person?

That's the state we find most of our people in. You're making them pay for their own misfortune, their own ill health. That to me sounds relatively precedent-setting. Or you're saying that these services should only be indulged in when people are well-moneyed. So I worry about that on the basis of equity.

**Mr Tilson:** We're starting to debate it and I don't think that's the purpose of this, other than to comment that, how far should the state go in subsidizing? I gather, just so I'm clear, you're saying completely. Is that what you're saying?

**Mr Young:** Fairly far. On the basis of protecting human rights—and I think that's what we're talking about here. When we talk about citizenship, rights and responsibilities of being a citizen, that hits me in the guts. That says something about my citizenship, being Canadian and what people have fought for.

**Mr Tilson:** Even if an estate can afford it?

**Mr Young:** Most can't. So if you're treating some as charity and others as a direct tax, I don't know; I find that doubtful.

**Mr Tilson:** To give you some solace, I can only repeat that no decisions with respect to fees have been made. The Attorney General will review that and comments like yours very seriously.

**Mr Young:** I hope so, but it is in the act as it stands now, so hopefully we'll see a—

**Mr Tilson:** Thank you.

**Mr Bernard Grandmaitre (Ottawa East):** On rights advisers, you say on page 4, "We strongly support an independently funded system of rights advisers." You realize that the commission is being eliminated?

**Mr Young:** That's the whole reason for the act; I understand that. But you should not have these hearings without somebody saying: "We liked that. We thought that was right and logical and an obligation of society." If you were to say that you must only talk within the philosophy of this bill, then we would be doing a disser-

vice to you. You should hear that some citizens are saying, "No, that's wrong." I'm sorry, I didn't mean to interrupt.

**Mr Grandmaître:** I just wanted your thoughts on the commission as it existed and its elimination. What are your thoughts?

**Mr Young:** I was very happy to see the rights adviser walk in right after the doctor told my son that he was being restrained, because I knew that would happen after I was gone. To me, that helped secure his citizenship. Now, the person might have come in and could have been completely incompetent. She was not. But at least there was a glimmer that the door wouldn't be locked without him knowing what he was up against. That's, to me, basic.

**Mr Grandmaître:** Being a very well respected organization or alliance, what has been your relationship with the ministry in the past, or now? Were you even consulted on this new bill?

**Mr Young:** No, but I'll give the ministry that easily because we were just formed last spring—we may sound like somebody else—in response to the mental health reform in Metropolitan Toronto. I was appointed to the steering committee and I said, "I need a base." You're not speaking much, Joyce, but Joyce knew she needed a base and we said, "Well, why don't we start pulling people together?" and that's what formed us.

**Mrs Caplan:** I met with members of your organization and we had a very good and productive meeting. I hope the government will listen to the concerns you have raised, but following Mr Tilson's answer when he said, "Trust us on cost recovery," which means user fees, given their attitude towards user fees, I'm not too optimistic.

I think the point you were making is that for those people, particularly who are on disability pension and have limited resources, to be forced into a heavy cost for services from the public guardian and trustee in and of itself is a form of abuse.

**Mr Young:** Yes, I believe that.

**Mrs Caplan:** I just wanted to get that on the record.

**Mr Young:** If you look at the economy of most mental health patients, 90% of them, their bank accounts are drained the first thing that happens, for many reasons. First of all, they're not earning, and then they need the social assistance. If you're looking for the trustee to make a profit off of it, they won't.

**Mrs Caplan:** It's not a question of profit; it's cost recovery.

**Mr Young:** Cost recovery: They're not going to do that.

**Mrs Caplan:** That's what they talk about. They're not making profits on this. It's a question of how much the taxpayer should pay and how much they should be able to charge as a user fee for those getting the service.

**Mr Young:** We see it as punishing the disadvantaged economically.

**Mrs Caplan:** That's an important point to make to this government, and hopefully they'll hear you.

**Mr Marchese:** Mr Young, I want to thank you for a number of points you've raised because I think that as a parent of a child who has particular problems, you bring

important insights to the whole matter. Your sense that people with disabilities or people with psychiatric problems have rights too is something that we value. I've made note of the fact that you're saying these are people with rights and should have them either restored or regained where necessary, or as a general principle they should have them.

I want to cover two points if I have the time to quickly mention them. One is to agree with you, and a number of people have said this, that where you have a rights adviser, and this only applies under the Mental Health Act, they now have changed the law that says it means a person or a member of a category of persons designated by a psychiatric facility—I want to ask Mr Tilson a quick question after I say this—and you pointed out that this is a conflict of interest, that it's a problem. What you said is that they should be independent.

**Mr Young:** Certainly.

**Mr Marchese:** The previous law said much to that effect, and I don't need to read it, but it allowed for what you were saying. Mr Tilson, he's not the only person coming from an association who's said this. A number of other groups continue to say this. Do you have an opinion?

**Mr Tilson:** There's a clear debate, obviously, about the issue of conflict of interest. I'm saying, you tell some health care provider, a nurse or a doctor, that they've got a conflict of interest. They're there to provide a service to individuals. You say they've got a conflict of interest. Quite frankly, it's a disagreement on philosophy. Those people are there to provide a service and we don't believe they've got a conflict of interest.

**Mr Marchese:** Mr Tilson, that's all I needed to know. Thank you.

The other quick question I wanted to ask is, under the Substitute Decisions Act, guardians now will be free to use restraints and monitoring devices without accountability. In the past they needed to have it as part of a guardianship plan. They now need not inform the court about this. Do you have an opinion on that?

**Mr Young:** That doesn't sound right. One more thing: I would agree with you that this should be looked at because those powers should not be used without accountability. But the doctor made an interesting point about neurosyphilis which, like schizophrenia, may not be considered a psychological disorder, but like schizophrenia, it affects how a person acts. Okay? It's exactly like schizophrenia in that it's a brain disorder chemically—well, in this case it's a viral problem, it's an infectious problem. Schizophrenia is more an inherited one, but they're both a physical disorder of the brain.

If he's restraining people under neurosyphilis without rights advisers, he should be ashamed of himself. He should be using rights advisers for them as well.

I agree with him that the standard for mental illness should be no different than the standard for physical illness. I agree with him totally there, and he's right. If you're going to provide rights advisers for mental illness, you should provide them—I'm sorry; I know I'm going over—for physical illness as well.

**The Chair:** Mr Young, I thank you very much for your presentation.



**Mr Young:** Thank you for the reception. I appreciate it.

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#### REENA

**The Chair:** Next is Reena, Mr David Cole.

**Mr David Cole:** My name is David Cole. I'm the vice-chairperson of the board of directors of Reena, and with me is Sandy Keshen, our executive director.

We would like, first, to express our appreciation to you and the members of the committee for receiving our brief on Bill 19 and giving us this opportunity to speak with you on this important legislation. We will not use this valuable time to read our brief, but we do want to explain the approach we have decided to take in our submission and to provide the context for the four recommendations we are making to amend the proposed Health Care Consent Act, 1995.

We will conclude our oral presentation by relating some of the events leading up to the deaths of two of our clients in Toronto hospitals in the past 12 months, deaths which involved delays in and withholding of necessary treatment by health care practitioners related to the issue of consent to treatment. Although the circumstances were very different, these client deaths have left us as primary caregivers feeling frustrated and powerless with our responsibility to support our clients and families in accessing the health care system.

Although the new Health Care Consent Act, 1995, has addressed some of the problems which may have been contributory to one of these deaths, without the amendments we are proposing, the vulnerable population we support will remain at risk in receiving timely and necessary health care.

Reena is a community agency which provides a range of support services including primary care for adults with developmental handicaps and their families. Our brief includes detailed information about us. We are a non-profit agency established in 1973 and operate under several provincial statutes and regulations, and work closely with the developmental services branch of the Ministry of Community and Social Services; that is to say, we are a credible community agency, well known in serving this special population. I would go so far as to say that we are respected and appreciated by both our clients and colleagues in the sector for providing quality services.

The approach we have taken with our brief is focused and concrete as compared with general and philosophical. We have decided not to argue the issues involved in the repeal of the Advocacy Act, 1992, and we comment only briefly in support of the proposed amendment to one section of the Substitute Decisions Act, 1992. Our focus rather is on the proposed Health Care Consent Act, 1995, which will replace the Consent to Treatment Act, 1992.

With respect to the new Health Care Consent Act, 1995, we have restricted our discussion to only four sections, those sections of the act which we believe to be most critical from the perspective of our clients and families and for agencies like Reena that are the primary caregivers in the community.

In our brief, we have discussed our concerns with respect to these four sections and have proposed specific amendments which we believe would address them and at the same time clarify and strengthen the intent of the legislation. Our purpose in providing you with exact text is to ensure that we have been as clear as possible in our communication, since we believe the problems we have identified can be resolved by the suggested amendments.

Our first recommendation deals with the definition of "informed consent" under part II, subsection 10(2) of the act. Fundamental to the definition of "informed consent" is the requirement of understanding. It doesn't matter how well treatment procedures and consequences of having or not having treatment are described to the person if the person receiving the information does not understand what is being communicated.

To ensure the protection of vulnerable populations, we have proposed that part II, subsection 10(2), include a clause to follow clauses (a) and (b) which states "the person is able to understand the information about the proposed treatment, and appreciate the consequences of having or refusing the treatment or of making no decision."

The second recommendation deals with the same issue of understanding but within the section dealing with the test for capacity, part II, subsection 16(1). While part I, subsection 3(1), provides a definition of "capacity" which contains the key requirement of understanding treatment information, these elements of the definition are not contained in part II in sections 14, 15, 16 and 17, which deal with the test for capacity. We believe the intent of the act would be clarified and strengthened with respect to the fundamental issue of capacity to give consent by a rewording of subsection 16(1), part II, and this rewording can be found on page 1 of our brief, which is recommendation 2.

Our third recommendation concerns the process by which a health practitioner assesses the person's capacity to give consent under part II, clauses 9(1)(a) and 9(1)(b). In our experience, it is unrealistic to expect that a health practitioner in general has sufficient knowledge and experience in meeting the health care needs of persons with developmental handicaps to reach valid or reliable opinions about the capacity of these persons to consent to treatment without consulting those who have expertise in this field. Again, for the protection of vulnerable populations, and respecting the difficult role of the health practitioner in these situations, we are suggesting the wording seen in recommendation 3 on page 2 of our brief.

The last recommendation we wish to speak to is number 4. Unlike the first three, it involves some controversy. It deals with the current dilemma that we, as primary caregivers, face in having the responsibility for ensuring that our clients have access to and receive timely and necessary health care, yet having no authority in determining that this is provided.

The current health care treatment continuum does not include the primary caregiver in the community as part of the health care loop or team when they are not a family member. This means we have no more status than a stranger does when approaching a health care facility or a practitioner with a client in need of health care services.

We are unable to authorize even the most basic health care procedure on behalf of our clients.

As well, critical client health care information we possess may be refused, disregarded or its validity challenged by health care practitioners when we are seeking health care services. Similarly, there is often a refusal of health care practitioners and facilities to exchange relevant discharge planning and treatment information with us due to legislation preventing release of patient information and right-to-privacy legislation.

We are asking that regulated community agencies which are the primary care providers of dependent populations be recognized within the new legislation as potential substitute decision-makers with respect to the provision of treatment, discharge planning and post-treatment care. We need to be included in the health care treatment loop if we are to support our clients and families effectively.

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In conclusion, we would like to share with you some of the events which preceded the death of two of our clients this year in Toronto hospitals. We believe that the new Health Care Consent Act, 1995, with the amendments we are proposing, would have prevented the death of a vital and engaging young man and the premature ending of the life of an elderly person.

The need for legislation which protects the health care rights of vulnerable populations is emphasized by examining the circumstances surrounding the death of the elderly person. Let's call him John. His premature death occurred prior to the proclamation of the Consent to Treatment Act, 1992. John had been diagnosed with Down syndrome and Alzheimer disease. At the time of his death, he was in his late 60s and had been living with us for 13 years. His mobility was restricted, and he required a wheelchair.

Two months prior to his death, John received emergency medical treatment for a seizure and was returned to the group home the same day. His general health declined following his return home, and on the advice of his neurologist John was readmitted to hospital two weeks later and treated for dehydration. He was returned home but was refusing food and, on the advice of the neurologist, was readmitted to hospital four days later. John continued to refuse food in hospital, and a feeding tube was inserted. John responded by pulling the feeding tube out and had to be restrained.

A conference with the hospital followed to determine whether John should return to his Reena home or whether chronic care was required. It was decided that Reena would apply for chronic care. The attending physician stated that a second option might be to consider palliative care. When asked by Reena staff to explain, he indicated that, as John was pulling out the feeding tube, he had indicated he did not want it and perhaps we should do as he wished. It was his opinion that John's quality of life was poor and maintaining his condition might not be in his best interests. When Reena staff disagreed with this option, the physician indicated that he had been in contact with John's cousin, his only family member, who had little contact with him, and that the cousin had agreed with the palliative option.

Ultimately, it was decided that Reena staff would assist the hospital with John's care while chronic care was being arranged and by having John visit his group home for short stays. The week before John's death, Reena staff who were providing 24-hour support in the hospital described John as eating one meal per day reasonably well, although the feeding took one to two hours to accomplish. They indicated that he was at times alert, smiled and laughed, appeared to recognize Reena staff, looked at magazines and sat up in his wheelchair.

John developed a temperature, was not treated with antibiotics and died in hospital of pneumonia a few days later. Reena protested without success the withholding of the necessary and appropriate treatment, to which John's cousin had consented.

There is no question that John's life was ended prematurely by treatment being withheld and that he did not consent to this decision. It was a very disturbing event for our staff, who continued to see John as a person and who recognized that, while it was true his quality of life was not good, he continued to experience small pleasures and appreciate his life.

While there are those who have concerns that primary caregivers like ourselves may not act in the best interests of clients, we believe cases like this one demonstrate that there are greater risks in excluding those primary caregivers from participation in health care treatment decisions who have established relationships and an understanding and communication with incapable persons.

The circumstances of the second death are different in almost all respects. In this case a young person with developmental handicaps was living semi-independently in his own apartment in the community. While I had changed the name, we received permission yesterday from his parents, and you have already heard about this case today, so I will use Lonnie's name. His name was Lonnie Clemens.

Lonnie was employed, had good social skills, and was outgoing and energetic. He was in good health and in regular contact with his parents. During one of her regular visits to his apartment, his support worker noted that Lonnie was unwell and arranged for him to be seen by his physician. Lonnie's doctor diagnosed constipation. Normally, the prescribed treatment would be done at home, but in Lonnie's case, due to his extreme aversion to any medical procedure, it was recommended that this be done in the emergency department of the hospital. Lonnie's doctor prepared a letter to the hospital emergency department in the fact that Lonnie was developmentally handicapped. Lonnie's doctor also telephoned the hospital to let them know Lonnie was on his way.

It was a Friday evening when Lonnie, accompanied by his parents, was seen in the emergency department. The attending physician asked Lonnie for his consent for the mildly invasive procedure required to treat his constipation and relieve his discomfort. Lonnie refused. The physician indicated to his parents that he could not begin treatment without Lonnie's consent. His parents pointed out that Lonnie was developmentally handicapped and, with his irrational fear of medical procedures, was not capable of giving or refusing consent. They produced the letter from Lonnie's physician and requested that the



attending physician consult the hospital's own records for confirmation since Lonnie had been treated there previously. The attending physician refused to accept the evidence of Lonnie's incapacity. Instead, Lonnie was admitted to the hospital for observation.

For the next two days, Lonnie's parents tried desperately to get Lonnie to consent to the procedure. He refused, even though he was now in considerable pain and discomfort. Reena also tried to intervene, at the request of the family, in support of their claim that Lonnie was not capable of refusing to give consent, but the hospital refused to listen to or consult with us.

Finally, on Monday morning, now in great distress and with a distended abdomen, Lonnie consented to the procedure. It was done but without result. A liquid purgative administered orally was then attempted, but as he was consuming the liquid too slowly, it was decided a feeding tube had to be inserted. Lonnie did not consent to this procedure and it was done by restraining him. During the procedure he gave assurance that if the restraints were removed, he would not pull the tube out. This was done but he immediately proceeded to remove the tube. The physician did not order further restraint or the reinsertion of the tube since he interpreted Lonnie's actions as indicating he did not consent to this procedure. No further treatment was given that day.

On Tuesday, further conservative treatment was attempted, with no success. Early the next morning, with his condition deteriorating, emergency surgery was performed. Lonnie died two hours later.

We believe Lonnie would be alive today if the principle of understanding contained in our first two recommendations had been applied, and if the attending physician and hospital had been willing to take into account the information as to Lonnie's handicap available from the family, Reena and another health care practitioner.

Finally, both deaths underscore the need for primary care agencies in the community serving vulnerable populations to be given status when they are seeking to meet the health care needs of their clients. We need the authority to obtain treatment for our clients when necessary and we need to have access to health care treatment information in order to provide appropriate home care for the same reason nursing staff in hospitals have access to patient charts and medical records.

This concludes our presentation. Thank you.

1500

**The Chair:** Thank you, Mr Cole. Each caucus has three minutes. Mr Grandmaitre?

**Mr Grandmaitre:** Actually, I wasn't present for most of the presentation so I'll pass on to the third party.

**Mrs Boyd:** Thank you very much. That was very painful for you, I could tell, and I think very painful for all of us to hear that obviously we don't yet have a situation that can protect vulnerable people in every case. Your recommendations are helpful. You understand that most of us tend to look at the other side where the caregiver may in fact have a conflict of interest that is really quite serious, and so it's very important for us to get that opposite point of view. I'm a little surprised that it wasn't possible for the hospital to deem this to be an emergency a little bit earlier than it did in the latter case,

and that's really quite distressing for sure, because that's what the provision in the act is supposed to do.

I'm going to ask you whether you also know of other cases. We've had several different witnesses, both in these hearings and in the Bill 26 hearings, who have indicated knowledge of cases where developmentally or physically disabled people going to hospital with conditions unrelated to their disability have been encouraged, or their substitute decision-makers have been encouraged, to agree to do-not-resuscitate orders on their charts. I wonder if in your experience you have heard from the families you serve whether there has been pressure in that regard for any of your clients.

**Mr Cole:** We are not aware of that information from our own families, but we are aware that in fact that has occurred from our contacts with other primary caregiving agencies in the community.

**Mrs Boyd:** It's a worry because one of the issues around substitute decision-making and being able to state ahead of time what your wishes are is that people who are in a terminal condition and want to give that instruction very often find themselves obstructed, and so it's very difficult to hear the opposite thing happening with otherwise very healthy people who have disabilities.

**Mr Cole:** I think one of the key points that we're making—I don't want to lose sight of that and we tried to be very clear about that in our recommendations. The controversial nature of the request we are making is to be included in the health care loop. When we look at the legislation, Bill 19, or even when we look at the old legislation in terms of what it was trying to do, in my view it was trying to respond to a health care system that is a 1960s health care system.

**Mrs Boyd:** That's right.

**Mr Cole:** What I'm saying is if we are moving now into the year 2000 and we're in the 1990s—we're moving out—we should be moving away from looking at recommendations even with the legislation that's coming forward now, and I think it is improved from the other—that meets the health care system of the late 1990s and going into the year 2000. I think the government is to be, in that respect, commended in its attempt now to make the delivery system both of health care and social services more streamlined, and to reduce the amount of bureaucracy, the amount of paperwork. I think we're drowning in this particular area in legislation in the health care and social services system as we are in other places.

What I'm saying is it does not make sense now at this point—it never did make sense, but it certainly does not make sense today as we are moving further and further into community care—to have two separate systems, the social service system and the health care system, which are not integrated. We have no status in the health care system. It is bizarre, given all of the regulations under which we operate as a primary care agency in the community. We are not out there operating on our own as an unregulated member of the private sector. We're very much an arm of government, and yet when it comes to the health care system we have no status at all.

In order that there are some protections for the client—and I agree with the comment that Mr Tilson made a while ago. We don't want to take responsibility away

from caregivers necessarily. I don't think there is a conflict, quite frankly, any more than there is a conflict with a medical practitioner or a nurse in providing assistance, that there's a conflict in a primary caregiver like Reena in supporting their clients and families in accessing the health care system. That's the point we're making. We have to be in the loop. Otherwise, these kinds of things will occur again.

**Mrs Johns:** Thank you very much, Mr Cole—

**Mr Marchese:** Mr Chair? Sorry to interrupt. Is there a time—

**The Chair:** No. You actually went over four minutes. *Interjections.*

**The Chair:** I didn't think that was the agreement. We can discuss that later. Mrs Johns, you have three minutes.

**Mrs Johns:** I'd like to draw your attention to one of the sections of the act, and I don't want to get really technical. Under subsection 3(1) of the act, it basically says that, "A person is capable with respect to a treatment, admission to a care facility or a personal assistance plan if the person," one, "is able to understand the information..." and two, is "able to appreciate the reasonably foreseeable consequences of a decision...." That's a definition that goes throughout the act that basically talks about whether a person is capable or not.

In the examples that you gave, especially in the second one, the ability to foresee the reasonable consequences of the act I would say would not be there.

**Mr Cole:** That's right.

**Mrs Johns:** What would have happened in the case of this new act, then, would be that the person would be seen to be incapable. A substitute decision-maker would have been set up. It probably would have been the parents, and this would have never happened. Is that not the case?

**Mr Cole:** Yes, that's true, but those provisions existed in the old legislation too and that test was not done. That's the problem.

**Mrs Johns:** Okay. So, if we make sure that these tests are done, then the bill meets the requirements that you have.

**Mr Cole:** It does, but it's strange to me that somehow or other—the definition that you give is under the section of definitions and it's sufficient. It could be better, it could be said better, but it would be sufficient. But when we look at the legislation under the section on treatment—and people often don't read all of those definitions. They'll go to looking at what in fact are they supposed to do when we look at the treatment provisions. When we go to the treatment provisions, there is no restatement of that definition as to what understanding means, or that understanding is the test that has to be used before consent can be made. What I'm saying is it needs to be included right there when the physician is attempting to determine whether consent is appropriate or not, and it's easy to include.

**The Chair:** I'm sorry, Mrs Johns, our time is up, unless Mr Grandmaître would give you part of his.

**Mr Grandmaître:** Thirty seconds and you're going to—

**The Chair:** I don't think we transfer—

**Mrs Johns:** I'm not your favourite person. Is that what you're saying?

**The Chair:** It's obvious that you have stimulated the committee into real concerns with the points you have raised, and I thank you very much for your presentation. 1510

#### AD HOC COALITION ON CONSENT, SUBSTITUTE DECISIONS AND ADVOCACY

**The Chair:** The Ad Hoc Coalition. I'd request that you identify yourself for the purposes of Hansard if you are going to be speaking before the committee.

**Ms Elisabeth Scarff:** Thank you, Mr Chairman. I'm Elisabeth Scarff from the College of Nurses of Ontario, and presenting with me today is Barb LeBlanc from the Ontario Medical Association. We're here today speaking on behalf of the Ad Hoc Coalition, which is comprised of representatives from the following organizations: the Alzheimer Association of Ontario, the College of Nurses of Ontario, the College of Physicians and Surgeons of Ontario, the Ontario Association of Non-Profit Homes and Services for Seniors, the Ontario Friends of Schizophrenics, the Ontario Hospital Association, the Ontario Medical Association and the Ontario Nursing Home Association. So you can see we're a mix of providers, facilities and client groups.

The Ad Hoc Coalition has focused mainly on the new Health Care Consent Act, but members of the coalition will comment or will have already commented on various aspects of Bill 19 in their individual presentations throughout the hearings. I might add that other representatives from other members of the coalition are also here present and will be able to answer questions later too.

The Ad Hoc Coalition is supportive of the directions taken in Bill 19. As some of you may know, the coalition has significant concerns with the existing legislation, many of which we put before the justice committee in 1992. Since the proclamation of the laws in April of last year, we have seen many of our predictions borne out in the implementation phase. To be it simply, the existing laws don't work in practice. They are too complex and unwieldy and they interfere with the timely provision of care to people who are incapable of making decisions about their own care and treatment. As a result, many health care providers cannot meet the letter of the law.

The Ad Hoc Coalition would prefer to see legislation that works. In our view, this means legislation that recognizes the caring and supportive role of health care providers and families, while recognizing that a small number of people will want to question a finding of incapacity that is made against him or her, and that for these individuals we support the availability of the Consent and Capacity Board as an appeals tribunal.

The Ad Hoc Coalition believes that Bill 19 removes most of the legislative barriers to care created by the existing Consent to Treatment Act and the Substitute Decisions Act.

In order to give the committee a better understanding of why we support the new Health Care Consent Act over its predecessor, perhaps we could provide a few examples of types of amendments that we view as positive.



The improvements in the definition section, including plan of treatment and course of treatment, serve to clarify government's legislative intent and to provide consistency in interpretation across disciplines and facilities.

Within the definition of treatment, we have found that moving the list of exclusions from the regulations into the body of the act will be helpful for health practitioners. The addition of clause (g), which introduces the notion of non-risky treatments, is very helpful.

It is also helpful in practice to have in legislation the idea that decisions about treatment include the withholding and withdrawal of treatment. The current law is unclear in this regard, and consequently providers, families and the Office of the Public Guardian and Trustee have struggled to know how to handle end-of-life decisions.

Similarly, the new Health Care Consent Act better reflects practice by acknowledging that minor variations to the same basic treatment are acceptable, as is the continuation of the treatment from one setting to another.

There are also a number of minor but useful amendments made in Bill 19 such as clarifications to the hierarchy of substitute decision-makers in regard to adoptive parents, in-laws, custodial versus non-custodial parents and legally separated spouses. The removal of the formal statement by family members attesting to their relationship with the incapable person is also useful. In addition, the Ad Hoc Coalition supports the changes made to the definition of emergency treatment under the bill, the ability of the Consent and Capacity Board to hear concerns from health care providers who do not believe that a substitute is acting in good faith and the clarification regarding protection from liability for health care practitioners who act in accordance with the act.

One of the significant areas of contention for some families and providers under the existing acts involves the difficulty in placing incapable persons into long-term-care facilities. The current Consent to Treatment Act indicates that admissions may be made only for the purposes of treatment. Tying admission to treatment has been extremely problematic, especially as many residents of long-term-care facilities do not require ongoing treatment in accordance with the act's definition of treatment. The solution adopted by the former government is both impractical and contrary to the principle that incapacity is situation- or issue-specific.

We believe that access to the hierarchy of substitutes is appropriate for admission decisions. We are therefore pleased that Bill 19 addresses in the Health Care Consent Act issues around consent to long-term-care facilities and does not require families to take the extraordinary step of making a guardianship application in order to make the necessary placement decisions. We are also pleased that it does not arbitrarily link treatment-specific incapacity to incapacity to make admission decisions.

Having spent some time on what we feel are improvements to the consent law, we would now like to turn for a moment to some of our concerns with the new Health Care Consent Act and to provide some rationale as to why some changes are needed.

**Ms Barbara LeBlanc:** We believe that it is appropriate to formally recognize daily routines as an important component of the health and wellbeing of an individual

and to acknowledge that many otherwise incapable people are capable of expressing wishes with regard to their daily routines even when they are not necessarily capable of consenting to an entire treatment and care plan. We do not believe, though, that the way it is presented in Bill 19 completely meets those objectives.

If government's purpose in adding part IV of the new Health Care Consent Act was to clarify that activities of daily living are separate and distinct from treatment and to provide the opportunity for access to the hierarchy of substitute deciders, then the Ad Hoc Coalition supports the intent.

We'd suggest, however, that the act creates new language to describe things that are already well understood in practice as "activities of daily living," or ADLs. The Ad Hoc Coalition believes that it would be helpful for everyone if the language in the act reflected common parlance and asks that the act speak of "assistance with activities of daily living" rather than the existing "personal assistance services." We would define activities of daily living as "an activity that the person performs routinely and may include activities such as hygiene, dressing, ambulation, washing, grooming, elimination and positioning or other routine activities of daily living." This language is taken from the regulations in the existing act and has in fact been found to work well in practice.

As it's written, Bill 19 provides a framework for decisions about activities of daily living only in the context of a care facility. We believe that the location of the treatment or care should not be the determining factor in setting the rules that are used. Rather, the law should look to the decision at hand and be applied consistently. We believe that this is more than a philosophical consideration and will become increasingly important as more care is delivered in the community. It's important that we don't inadvertently create situations where the only way to obtain the necessary consent for an incapable person will be by means of placement in a health care facility.

In our original presentation on the Consent to Treatment Act, the Ad Hoc Coalition expressed some concerns regarding the fact that the provisions of the act were much more onerous where it came to mental illness and admissions for psychiatric treatment than for physical illness. Those same concerns hold today. Although the Health Care Consent Act addresses many of the legislative barriers to timely care for patients with physical illness, it doesn't do the same for mental illness. The Ad Hoc Coalition believes that mental illness should be treated in law the same as other diseases.

Just to conclude, the Ad Hoc Coalition commends the government for moving forward with amendments to the consent and substitute decisions acts. We believe that the key principles which should be incorporated into a consent law are generally found in the new Health Care Consent Act, and having had an opportunity to work with the existing laws for some months, we believe it's important for the Health Care Consent Act to provide certain things, and that includes clear legislative authority for substituted decision-making for all health care, regardless of whether it's treatment as defined under the act or at common law, activities of daily living and decisions regarding admission to care facilities.



As Elisabeth noted, our individual organizations will be providing more detailed comments, but we hope these comments are of some use to the committee and we'd be pleased to open it up for questions.

**The Chair:** We have approximately five minutes each.  
1520

**Mr Marchese:** I have a question and I want to read from a document that ARCH presented. It has to do with admission to a care facility without consent. They say:

"One of the amendments introduced in Bill 19 would permit a person to be admitted to a care facility without their consent or the consent of a substitute where there is a crisis. This provision has great potential for abuse. It's difficult to think of a situation where this type of admission would be required for the benefit of the individual. However, it is not hard to think of circumstances where a hospital may use this provision to transfer a patient who does not want to be admitted to a care facility."

Do you have a comment in that regard?

**Ms LeBlanc:** I think the original Consent to Treatment Act in fact had that same provision. It did allow for admission over objection except in the instance of psychiatric admissions, so we don't really have anything tremendously different from the existing legislation.

**Mrs Boyd:** If I may, I think the issue they were raising was the area of the new act that talks about continuation of service including a transfer to another facility. That is what ARCH was most anxious about.

**Ms Scarff:** I don't think that we have read the changes in the act to say that the transfer provisions allow for moving over without consent. The transfer provisions allow that treatment decisions that have consent can follow through, which has been quite a problem when you already have a plan of treatment that's been consented to.

**Mrs Boyd:** I understand that's the intention. I understood them to be saying that their concern was that the clause about continuation might indicate that a transfer could occur without another consent. I may be wrong, but that was what I understood their concern to be.

**Ms Scarff:** Deborah, do you want to address it?

**Ms Deborah Wall-Armstrong:** Debbie Wall-Armstrong, with the Ontario Nursing Home Association. One of the things I can tell you, though, for people going into our facilities, before that can even happen you have the intervention of the government placement coordination services, so there are still some other checks and balances to the system. I'm not sure what facility other than a long-term-care facility ARCH would be concerned with. But there are those checks and balances; the placement coordination services have their criteria that have to be looked at for individuals to suit their needs on it. So there is already a government check in place.

**Mr Marchese:** With respect to rights advisers, we've had a number of organizations that have come before this committee and talked about the need to continue to have rights advisers in order to protect individuals who may not have a family or where there might be abuse or where abuse could happen in general. I tend to believe the rights advisers are important as a way of protecting vulnerable individuals. Do you have an opinion on what

this government is doing with respect to the elimination of the commission and rights advisers altogether?

**Ms Scarff:** The Ad Hoc Coalition as a coalition does not have a position on that. Members of the Ad Hoc Coalition have made their individual views known in their individual submissions.

**Ms LeBlanc:** Just perhaps to follow up on that, at our most recent meeting as a group we wanted the committee to have an understanding of what the rights advice provisions mean. There is a form that starts with the printing of the patient's full name and address, telephone number, the name and address of the facility, if any, the full name of the health care practitioner, and then asks the practitioner to read: "The Consent to Treatment Act provides a complete guide to making treatment decisions. It sets out rules that your health practitioner must follow. The goal of the act is to ensure that your wishes are respected and your rights protected. The act requires your health practitioner to give the following information: This is to inform you that at this time you have been found incapable of consenting to" whatever. "This means that someone will be making a decision about this treatment on your behalf in accordance with the Consent to Treatment Act.

"If you disagree with this finding, you are entitled to apply to the Consent and Capacity Review Board to review the finding that you are incapable. You are entitled to meet with a rights adviser. The rights adviser will explain to you what your rights are. He or she will help you to apply for a hearing to review the finding that you are incapable if that is what you want to do. The form you need to apply to the board is available from a rights adviser at the regional offices of the board and may be available from the facility where you are staying."

You then must sign, date, get the signature of the practitioner, full name of practitioner, decide whether or not a meeting is requested, and you must send by fax, if possible, a copy to the rights adviser as well as providing a copy to the allegedly incapable person.

**Mr Marchese:** Can I ask you, by the tone in which you read it, obviously—

**The Chair:** Your time is up. Excuse me, Mr Marchese, they have five minutes. Mr Tilson first, and Mrs Johns, who raised her hand.

**Mr Tilson:** I have a quick question with respect to the personal assistance plans and your recommendation of a change to the act. I found it an interesting one. I'd like you to elaborate a little bit on it. It had to do with activities of daily living versus assistance with activities of daily living, and I suppose someone better than I can deal with those wordings.

What did interest me in a suggested amendment which I'd like to hear more about is the location, particularly when we're getting into more care outside of facilities, and your suggestion that "the location of the treatment or care should not be the determining factor in setting the rules that are used. Rather, the law should look to the decision at hand and be applied consistently." A very simple statement; I understand it, but perhaps you could elaborate a little bit more on it.

**Ms Scarff:** Part IV of the Health Care Consent Act as it's presently proposed says that in the case where you



need consent—or you want to get consent, which is another issue—to activities of daily living, you can refer to the substitute hierarchy if the person is not capable of consenting. But that's based on where the treatment is provided.

Our simple concern is, what's that got to do with why you would go to the substitute hierarchy to obtain consent? If you need access to consent and you want to have certainty about who is authorized to give that consent, the fact that you're in a care facility as defined in the act doesn't really have any relevance, because what happens to all those activities of daily living in other facilities?

**Mr Tilson:** It's a good observation and I'm sure it will be considered. Thank you.

**Mrs Johns:** We've heard a great deal about incapable persons and their right to have rights advice and to hear that they are incapable and to know that decision is being made about them. There's lots of talk about how we should do that, and since you represent a number of professional groups I'd like to get your vision on whether it should be demanded in legislation, put in regulations or whether it should be guidelines from the professions that you are representing.

**Ms LeBlanc:** As Elisabeth alluded to, as a coalition we haven't worked out a fulsome description of rights advice, but as a group we tend to agree that it ought not to be in the legislation, that it should be viewed as a matter for professional regulation judgement and that the various colleges could perhaps do something with it.

**Mr Grandmaître:** In your presentation you didn't address the practitioners who do the capacity assessments. What are your thoughts? Do you think that this is well addressed in the new legislation, that you have no qualms about it?

**Ms LeBlanc:** Just for clarification, are you speaking of the capacity assessments under the Substitute Decisions Act?

**Mr Grandmaître:** Yes.

**Ms LeBlanc:** Actually, as a group we really haven't spent a lot of time on the Substitute Decisions Act. I'm not sure that we've really talked about it.

**Ms Scarff:** No, we haven't really talked about that aspect of the Substitute Decisions Act. I'm trying to think of the area that you think we might have concerns about.

**Mr Grandmaître:** A lot of people, from certain groups anyway, have mentioned that they're quite concerned about the quality of the people who are doing these assessments and the lack of qualification in these people. I just wanted to know what your thoughts are because I think it's very important for people like you to make sure that those assessments are made by the right people, by qualified people, by trained people.

**Ms LeBlanc:** I guess the closest we come is that a number of the people on the Ad Hoc Coalition also sit on the government's interim advisory committee on substitute decisions, and that's an issue they've spent a fair bit of time on. Unfortunately, that's the extent that we can comment.

**Mr Grandmaître:** Thank you.

1530

## ONTARIO NURSING HOME ASSOCIATION

**The Chair:** The next submission will be made by the Ontario Nursing Home Association. Carla Pepler.

**Ms Carla Pepler:** That's me.

**The Chair:** Could you identify the other two for the purpose of the Hansard record.

**Ms Shelley Jamieson:** Good afternoon. My name is Shelley Jamieson. I'm the executive director of the Ontario Nursing Home Association. That gives me the privilege of being the chief flag waver at events like this. With me are Carla Pepler and Deborah Wall-Armstrong.

I'd like to introduce my colleagues in a little more detail and then provide some overall context for our submission. Then I'll be turning the presentation over to the experts who are with me today.

Deborah Wall-Armstrong is a lawyer with her own practice in Barrie. She's a former board member of the Ontario Nursing Home Association and she's also the owner and manager of a nursing home. Carla Pepler works with me at the Ontario Nursing Home Association. She's the director of policy and resident care. Carla has a bachelor of nursing science, as well as a master's in public administration, and has been with our organization for 12 years. Both of these women have devoted a phenomenal amount of time over the past four years to understanding firstly the three acts which came previous to this one and now the Health Care Consent Act. As such, I'm sure that the committee will find their comments both informed and insightful.

By way of background, you should now that ONHA represents 302 nursing homes in Ontario, both for-profit and not-for-profit facilities. Our members have the massive responsibility, in my opinion, to care for 30,000 of Ontario's most frail and often vulnerable citizens. That's why the previous bills and this one are so important to us as an organization. We too take the safeguarding of residents' rights very seriously.

While we endorsed the intent of the previous acts, we became very concerned about some of the elements which may have worked on paper but in fact did not work on units in nursing homes. Of grave concern to us was that the very laws intended to protect residents were in fact increasing their vulnerability and complicating their lives. ONHA is extremely pleased with the changes proposed in the new Health Care Consent Act. The changes will allow for more responsive care environments because they will facilitate the provision of care in a much more timely fashion.

I wish to draw the committee's attention to the reference list on page 2 of our brief which shows the many elements of Bill 19 which ONHA supports. There's a whole list there. I'm not prepared to read them into the record; I know you'll be reading them. I think we should turn our attention to the rest of the presentation. We thank you really sincerely for the opportunity to be here today. My colleagues will now present what we feel are areas which could be considered for improvement to the bill. We sincerely hope that all parties will give these issues serious consideration.

**Ms Deborah Wall-Armstrong:** As Shelley has said, we are quite pleased with the act and we've listed about

21 changes on page 2 that we're particularly pleased with. I'd like just to highlight some of the most significant for us. They include the simplified consent process; the expanded definition of "plan of treatment"; the inclusion of withdrawal of treatment as part of the definition of "treatment"; the expanded list of substitutes and the non-custodial parent clarification; also the removal of the need for treatment in order to be admitted to a long-term care facility.

As I say, you can tell from that list that we're generally pleased with the bill. However, we do have a few areas of concern that Carla and I would like to point out, along with some suggested possible solutions.

Clause 19(2)(c) of the Health Care Consent Act outlines a test for best interests that substitutes must use, and the factors that should be taken into consideration when deciding what the incapable person's best interests are. This section is reproduced for you on page 3 of our submission.

Substitute decision-makers for nursing home residents must look to this test when making decisions on behalf of a resident, particularly when the decisions involve non-treatment, do-not-resuscitate orders or the withdrawal of treatment. Clause 19(2)(c) is written in such a way that it leaves a substitute to think that they should always choose to treat, which is inconsistent with changes made in this act to recognize that a refusal of consent includes withdrawal of consent. Substitutes are allowed, under subsection 19(1), to refuse consent. The inclusion in subsection 19(2) of such words to describe treatment as "likely to improve" or "prevent or reduce deterioration" imply that a treatment should be given. There are no words in the best-interests section that lead the substitute decision-maker to consider the benefits of non-treatment or withdrawal of treatment. Families oftentimes therefore feel that they should not choose the option of non-treatment or withdrawal of treatment, and there are times when non-treatment or withdrawal of treatment are in the incapable person's best interests.

Therefore, the best-interests test we feel should be balanced between the two extremes of treatment and non-treatment to fully integrate the concept that non-treatment or withdrawal of treatment are some of the choices for a substitute decider. On the bottom of page 3 and the top of page 4 in our paper, we suggest a rewording of this part of the legislation to achieve this, by inserting the concept of quality of life into the factors and specifically asking the substitute to consider whether the treatment is likely to prolong the incapable person's suffering as an additional factor in the best-interests test.

In addition, we have some concern on the definition of "emergency." Subsection 23(1) of the Health Care Consent Act, which has the definition, is reproduced on page 4 of the paper. We support the addition of the term "apparently" to the definition, but that change is not sufficient to deal with the problem we're experiencing with some medical emergencies. In practice, under the existing legislation, and it would be true under this as well then, the definition, rightly or wrongly, is being interpreted as applying only to physical suffering because of the inclusion of the phrase "bodily harm." Occasionally residents experience both physical and mental suffer-

ing, and they are at risk of sustaining serious physical and/or mental harm if not treated.

If I have a resident with an adverse drug reaction who has become delusional, thinks there's something crawling on them, they may become extremely agitated, they may start scratching at themselves, they may damage their skin, cause further infections to themselves. Recognizing that I'm dealing with a very frail population here that cannot take a lot of abuse, once restrained, they may not be in danger of direct physical harm, but they'll suffer the emotional effects of having to be restrained. If the problem is truly drug-related, there may be other brain damage to the individual if they're not immediately treated. We would ask that you consider the following amendment to address that concern, by putting "mental suffering" into the definition of "treatment." A suggested rewording would indicate, "For the purposes of this section and section 25, there is an emergency if the person for whom the treatment is proposed is apparently experiencing severe mental or physical suffering or is at risk, if the treatment is not administered promptly, of suffering seriously bodily harm."

At this point, I'd like to turn the microphone over to Carla to outline some of our other concerns with the Health Care Consent Act.

1540

**Ms Peppler:** I'd like to start with admission to a long-term-care facility. We are very pleased with removal of admission to a long-term-care facility for the purposes of treatment. This current approach in the Consent to Treatment Act has made consent to admission very problematic. The proposed section 38 requires that an evaluator determine whether or not a person is capable of consent to his or her admission to a long-term-care facility. The bill outlines who an evaluator might be, and that includes a nurse, a physician, a psychologist, occupational therapist, physio and a few others.

Currently, with placement coordination services, or PCS, they generally use nurses or social workers to do their assessments on all potential applicants to long-term-care facilities. In order to support the current process, we recommend that the regulations governing who an evaluator could be include social workers.

Also in the past, placement coordination services have had difficulty obtaining consents to admission, as various community-based agencies, by policy, did not allow their staff to complete capacity determinations for admission or obtain the consents. This has led to the current situation where we rely on physicians to test capacity and obtain the consent. In order to avoid this situation happening again, government must provide guidelines to all potential evaluators on the how-tos of capacity determination. This type of capacity determination will be a new skill for many, if not most, of these evaluators and therefore education will be required. If education does not occur, the system may revert to the current situation where only physicians will be asked to do the capacity determinations and obtain the consents.

I'd now like to turn to the personal assistance service plans. Most of the residents in our facilities have some degree of cognitive impairment and this limits their ability to make their own decisions. Our staff are very aware



of this issue and try hard to encourage residents to make as many decisions for themselves as they possibly can. This, we believe, helps residents to maintain as much control over their environment and their care as possible. We assume that no matter how confused a resident may appear to be, he or she can indicate to us whether they want to be toileted or fed or bathed at any particular point in time. We believe that the capacity test for a specific personal activity is very low, therefore implying that most residents, except maybe those in a coma or those who are totally unable to communicate by any means, are capable of making decision about their specific personal activities.

The decisions involved in determining an actual personal assistance plan are at a much higher level than the determination of an actual personal assistance service. Section 4 of the Health Care Consent Act looks at capacity to make the plan. When developing a plan, considerations such as the timing of particular activities to support the resident's past practices and enhance their current strengths and abilities, the amount and type of intervention required by staff, the kinds of assistive devices that are required, the kind of communication, the kind of support required, all of these factors are taken into account when developing that care plan and each one requires a lot of judgement about the benefits and consequences of each option.

Unfortunately, most nursing home residents don't have the capacity to make this level of decision. So by focusing on the capacity for the plan instead of the specific activity, the rights of many of the residents to make their own decisions about daily aspects of care could be removed. We support resident autonomy. As a result, we recommend that section 4 deal with the capacity to make a decision about a specific activity rather than the plan as a whole. Because there are some residents, however, who will not be able to consent to an activity of daily living, we do recommend the inclusion of the concept of the plan with access to the hierarchy for consent purposes.

It's not clear to us why this section pertains only to residents of long-term-care facilities and not to persons in other health care sectors, such as chronic hospitals, acute care hospitals and the community, where personal assistance plans already exist.

Long-term-care facilities have detailed requirements in our Nursing Homes Act and in our program standards manual that outline what has to go into a plan of care and how it's developed and how families and residents should be participants in that process. Of all of the various health care settings, long-term-care facilities have the most rigid safeguards in place with respect to plans of care.

The inconsistency of location must be removed so that all persons and all personal assistance plans are treated the same. It should be the action and not the location that should be the determining factor here.

Another issue is the fact that the proposed act creates a new language to describe things which are commonly understood in practice as activities of daily living. The definition of "personal assistance service" included in the act is also not commonly used as the definition of

"activity of daily living." As a result, this has led to much confusion about the intent of section 4.

To better support current practice and the public's general understanding of what we believe is the intent of this section, we recommend that the term "personal assistance service" be changed to "activity of daily living" and that the definition of "activity of daily living" that's currently included in the Consent to Treatment Act regs be used to define "activity of daily living" in this new act.

It's important to remember, however, that this new section will not assist care providers to give care to uncooperative residents. If a resident flatly refuses to participate in a care activity, having consent to a personal assistance plan or an activity of daily living plan will not help the staff complete the activity with the resident. We consider it abuse to force a resident to do something that they don't want to do. So the care issues associated with a psychogeriatric resident will not be resolved by Bill 19.

At times, we found it difficult to obtain a consent from a substitute decision-maker in specific circumstances and have therefore been unable to proceed with basic personal care and comfort measures, and this has put some residents at some degree of risk and discomfort. In order to facilities effective safe care and comfort, the addition of a provision which allows the health practitioner to provide the necessary assistance with activities of daily living to maintain resident comfort and dignity would be extremely advantageous to the resident. This type of provision would be similar to the emergency treatment provisions in section 2.

In summary then, we recommend:

(1) That the threshold for capacity be changed from the plan to the specific activity.

(2) That the term "personal assistance service" be changed to "activity of daily living".

(3) That "activity of daily living" and "activity of daily living plans" not be restricted by type of facility.

(4) That the ability of the health care practitioner to provide comfort and assistance with activities of daily living to incapable persons who do not have a substitute decision-maker readily available be added to facilitate the resident's comfort, dignity and wellbeing. I'll turn it back to Debbie.

**Ms Wall-Armstrong:** What you've heard are a few of the concerns we had with regard to the Health Care Consent Act, but we have some other concerns as well—just a couple. I'd like to point out that on page 10 we point out that although we're supportive of the expansion of options available to the public guardian and trustee under the Substitute Decisions Act, we're concerned from our past experience that the threshold for action or investigation by the PGT hasn't changed.

The incidence of families not providing for residents' financial needs is increasing. Not only has this been found anecdotally by surveying nursing home staff, but a recent survey by the Ontario Residential Care Association also suggests that incidence of financial abuse of residents is on the rise. Not only do families not pay for the residents' accommodation, but the residents are not given any money to pay for such things as clothing, hair-dressing, outings, tuck shop purchases, ironing, mending,



personal wheelchair maintenance and drugs not covered by the ODB. To date, the public guardian and trustee will not investigate such allegations of abuse.

The PGT states that such cases do not result in serious adverse effects for the residents at nursing homes because nursing homes are not allowed to discharge a resident for non-payment of accommodation. Therefore, the residents' care needs will be met and they will not be at risk. They also state that they're not bill collectors for the long-term-care association.

We differ very strongly in what we feel the role is for the PGT here because we feel that the residents' quality of life is directly affected by not having access to funds to meet their needs and wishes. Although we may have an obligation to take care of their basic care needs, if they can't even access it to buy new clothing when they need it, have their hair done, it all has a psychological-social impact upon the residents themselves.

Nothing's more pathetic than to recognize you've got a resident here who has funds, they know they may have funds and I'm going up to my closet of used clothing that somebody has donated to our home to find them something to wear. It's pathetic. To see elderly, frail people left in that situation is sad, it's absolutely sad. I think that there's a role and responsibility that needs to be assumed here with it. The emotional impact of course is definitely there and I think that does affect their actual needs.

We'd urge the government to state, either in statute or by policy, that the public guardian and trustee has a role to investigate such cases. We believe that many of the cases can be resolved without an application for temporary guardianship.

We found in the past ourselves, and I've been involved in cases directly where we had the same problem with the use of federal funds coming in to a resident and the administrator of the home has contacted the federal government and said a family member is taking these moneys. The federal government has been quite prepared to direct the funds for certain federal pensions to the home as long as the home agrees to administer the funds without cost and be open to audit at any time.

Just the fact that the ability is there oftentimes stops family members from messing around with the funds. They do what they're supposed to do; they take care of the resident's needs. I think the same thing would be true if the public guardian and trustee's office had the authority to investigate and did at times investigate. Obviously, they'll need reasonable parameters within which to do that, but just the very threat that they could go in and investigate will probably in most cases take care of a lot of the problems and people will start to address that need.

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Currently, we also need health care providers and the public to generally know what the criteria are, what the indicators are that the PGT uses for actual investigating. Sometimes the PGT's office gets calls that it shouldn't be getting and doesn't get other calls it should because it's not well known, what do you investigate? I think health care providers and the public generally need to know that. I also think the repeal of the Advocacy Act probably heightens the need for that type of investigation to be carried out by the PGT. Without us having a lot of

layering of legislation under the Advocacy Act, this is one way to ensure that this kind of concern or problem has some way of being dealt with.

We also have a little concern on the disclosure for personal information that we've outlined here. We strongly want to recommend that under—it's actually subsection 60(3) of Bill 19, which we've incorrectly noted I think as subsection 90(3), which amends section 90 of the Substitute Decisions Act. There is a right to disclose some personal information. We have a concern on how that will actually take place. We understand that there are some specific situations that need to be addressed by this section, but it should be done in a manner that continues to reinforce an individual's right to privacy in regard to their medical information wherever possible. The section authorizes but does not mandate the release of the information, so we strongly feel there should be some consultation on the development of regulations under this section to address issues of individual privacy and reinforce guidelines that health care providers should use before releasing this information, and those guidelines need to be in place before that section of the act is actually proclaimed in force.

As I say, we're pleased with the majority of the changes. There are some suggestions that we have very specifically put forward to you. We'd be happy to answer any questions.

**The Vice-Chair:** I want to thank you for your presentation. We will have a few questions now. We've got about two minutes per caucus and we'll start with the government side.

**Mrs Johns:** That's tough with only two minutes. At pages 3 and 4 of your presentation you're talking about 19(2)(c), and I admit I have a lot of trouble following what you're saying. You're basically saying in this section that we're promoting treatment, although when we talk about this, we're talking about what the incapable person's best interests are, the person who gives or refuses consent, so we talk about a pro or a con of that. We ask you to look at the person's beliefs, and then we go through these things as you suggest. You want us to put in "quality of life" and "prolong the incapable person's suffering." I have a lot of trouble with that in the fact that quality of life to me is very different from what it is to you or to someone else in this room. Can you talk to me about why that's so important to you and why you think those words should be in there?

**Ms Pepler:** We've had a number of families who are struggling with questions about advance directives, like whether or not CPR should be initiated, for example. When they're trying to make that decision, they go to the current Consent to Treatment Act. This is the best-interests test, and they feel when they read this that it's telling them they'd better choose CPR.

**Mrs Johns:** They can refuse treatment.

**Ms Pepler:** Even though they use quality of life from what they believe is the resident's perspective, they still come out feeling that the act is telling them to choose treatment over non-treatment or withdrawal of treatment.

**Ms Wall-Armstrong:** I think the issue is, subsection 19(1) specifically talks about withdrawal of treatment being part of the treatment aspect, but people often don't



even look at that. They really look at the next part, which deals mainly with and the wording really speaks to treatment. It may be more of an educational process, but just because of the difficulty we've had in the past with it, we wanted to make sure that it was quite clear to everybody that non-treatment or the withdrawal of treatment was in fact part of a treatment to be considered.

**Mrs Johns:** One of the things I'm surprised about is your personal assistance plans and you suggesting that it should be done on a very micromanaged area, as opposed to on the plan. I can understand your focus on that, but what I'm concerned about is that we have to then get acceptance for toileting, we have to get acceptance for bathing, we have to get acceptance for every aspect in the day. You'll be spending more time doing paperwork than anything else that I can think of.

**Ms Wall-Armstrong:** What we're saying is we're quite content with the substitute making the decision about the overall care plan, because in most cases the resident can't do that; it's far too complex when you put all those factors in place. But it also gives the presumption that the health care provider no longer has to individually, when the incident comes up, whether it's feeding or toileting the individual, get their consent to it, that somehow they're supposed to make them do and follow this plan. We don't believe that in fact is true. We believe the individual still has to make that decision. If they're not going to consent to eat, then we may have to, if it gets to another emergency situation, treat them in some fashion with a feeding tube, but people aren't going to sit there and shove a spoon down their throat or try and pry their mouth open in order to shove food at them. It's still an individual decision and the capacity to make that decision is at a very low level.

**The Vice-Chair:** I'm sorry. I'm going to have to stop you there. We have to move on to the Liberal caucus and Ms Caplan.

**Mrs Caplan:** On page 13 you say, "We feel that there needs to be consultation on the development of regulations." Was the Ontario Nursing Home Association part of a consultation with the minister on the developing of this legislation? Did you meet with the minister to discuss the Consent to Treatment Act and any of the concerns, or with the Attorney General?

**Ms Peppler:** Not directly with the minister, but we have met with ministry staff and talked through issues.

**Mrs Caplan:** Did you give them the advice that you gave in this brief during those consultations? Did they share with you what they were proposing? I'm just wondering why they didn't listen to any of the things that you suggested during the consultation.

**Mrs Johns:** Oh, Elinor.

**Mrs Caplan:** No, you know—

**Mrs Johns:** We didn't listen to one thing they said? They like the bill.

**Ms Wall-Armstrong:** On those issues, we didn't have any extensive consultation about that particular section, but I think that staff were not opposed to the suggestion we're making that there be continued consultation. I think they recognize what concern we had.

**Mrs Caplan:** Were you given any assurance that there would be consultation on the development of the regulations?

**Ms Wall-Armstrong:** No. I think it would depend on the direction from the government itself.

**Mrs Caplan:** That's the concern that I have. Frankly, I was surprised at the questions from Mrs Johns, because you made a very powerful presentation about the number of individuals who are abandoned by their families or treated in a way which is contrary to the government's belief that all families act in the best interests of their loved ones. That really worries me. I must admit that I hadn't heard you say that in a while and I had kind of hoped that things had improved. They haven't?

**Ms Jamieson:** They're getting worse.

**The Vice-Chair:** Ms Caplan, I'm sorry.

**Mrs Caplan:** I guess I would just put a pitch in. I think the chill factor that you recommended, which is the kind of accountability balance, is something the government should consider, because nobody wants the public guardian and trustee to be able to walk in, but the opportunity for them to investigate where you've expressed a concern I think is a good idea.

**The Vice-Chair:** Ms Caplan, I'm sorry. I'm going to have to cut you off there. Ms Boyd, you're next.

**Mrs Boyd:** I think since the powers of attorney for property are also included in Bill 19, when we go through clause-by-clause one of the things we'll have to look at is a way in which we can ensure that someone who has the power of attorney for personal property and who is not fulfilling those obligations when someone is in a care facility—that really worries me. I've always worried about what happens if the personal care decider is different from the power of attorney for property and they don't agree and they order this kind of treatment and then the money isn't there. That's always worried me.

I want to just speak a little bit on the quality of life thing. We've heard from many of the disabled groups how very worried they would be if quality of life were there and talking about suggestions about do-not-resuscitate orders, because of an assumption that somebody has that if somebody is disabled, they don't have a good quality of life. So while I agree with you that there needs to be a way that people understand that withdrawal or refusal of treatment is part of the consent, I can assure you that you would hear howls of outrage from the disabled community if you were to add this "quality of life" or "prolong the incapable person's suffering" to the act the way it is. I agree with you that we have to do better education around what that permission means, but the cases that have come forward are very good examples of why somebody's subjective decision about what somebody else's quality of life is is a very slippery slope.

**Ms Wall-Armstrong:** I must disagree in part when I heard the case earlier. I think the case really points out the fact that the health care person involved, and particularly in that young person's case, has not had a solid enough education about the new legislation. It speaks to the complication of the previous legislation, the three acts together. There was to be an educational process for health care providers that was shortened up dramatically before the legislation was passed and there's been a lot of confusion among health care providers about the legislation itself that still has not been straightened out. There's still a marked educational factor that needs to be brought forward for health care providers.



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**Ms Pepler:** We also work with our staff to have them work with the families to have the families look at the values and beliefs of the resident and incorporate that into their decision-making. We try very hard to focus on that.

**Mrs Boyd:** Could I ask one little question?

**The Vice-Chair:** Very quickly.

**Mrs Boyd:** Is feeding and hydration an activity of daily living or is it a treatment?

**Ms Pepler:** It would depend. If feeding is a tube feed, that would be a treatment, but if you're helping someone with a regular plate of food, that would be an activity of daily living.

**Mrs Boyd:** That's another area that we've heard a lot of concern about.

**The Vice-Chair:** I want to thank all of you on behalf of the committee for your presentation. It was certainly very helpful and I appreciate that.

#### HIV AND AIDS LEGAL CLINIC ONTARIO

**The Vice-Chair:** The next presentation will be from Mr Jeffrey Cowan for the HIV and AIDS Legal Clinic Ontario.

**Mr Jeffrey Cowan:** Good afternoon. Sitting beside me is Alex Brooks. He's our community legal worker at the legal clinic.

May I start by introducing ourselves? We are a brand-new organization that has been funded by the government in a variety of capacities, and as such we have three particular mandates. One of them is to provide legal services and advocacy for individuals living with HIV and AIDS, the second one is an education mandate and the third one is a law reform mandate.

Unfortunately, we became aware of these hearings late last week and therefore have not had adequate time to fully analyse the bill in detail. However, we have managed to put together a brief that addresses from our particular standpoint a variety of issues that affect the community we represent.

I would just draw your attention on the first page of our brief to our principles, which I will read quickly, that outline the fact that we believe in the rights of individuals to exercise control over their own medical treatment, to make decisions concerning their economic position, to be fully informed about all processes and to consent or withhold their consent in all matters. Therefore I would put forward to you that our interests are directly on point with this legislation.

At the risk of stating the obvious to the individuals present here today, I would say that people living with HIV and AIDS are almost always faced with issues of capacity, consent, health care decisions and the right of self-determination. As you may or not know, dementia is one of the major developments of this disease, and therefore a lot of people are found incapable of carrying on their affairs as the disease progresses.

Our submissions will cover three particular factors because of the short time period that we had to look at this. One is general considerations, which I would put forward to the committee they would look at very briefly; second is specific statutory considerations; and then some conclusions that we've come up with.

As our organization is a grass-roots organization, we are dealing with a marginal community of affected individuals. The definition of "family" therefore in the legislation, both the new legislation and the past legislation, is of extreme importance to us. The statistics would indicate that 80% of the individuals affected by our disease are gay males. However, there are intravenous drug users and single women, and that portion is increasing. Unfortunately, due to the marginal nature of the individuals we represent, they do not have the family support that a lot of the other groups you've spoken to have. Therefore, there is one particular individual, and we'll call them the preferred individual of choice, who is not represented in the definition of "family."

It was nice to see that when the legislation was changed in 1995 or came into being in 1995, they brought in a definition of "partner." However, I suggest to you that in a variety of circumstances, in almost a majority of circumstances, it is neither the family, nor is there a partner, who is making the decisions for these individuals; it is a friend, a colleague, someone who has nothing to do in terms of bloodline or of relationship with the individual on an intimate basis who is helping make these decisions. So I suggest to you that you expand the definition of "family."

Because these individuals are marginalized, they're vulnerable, and there is a particular interest on our part to have some form of advocacy of a third party. That does not mean millions of dollars need to be spent on an Advocacy Commission. I realize one of the reasons the Advocacy Act is being repealed is the cumbersome nature of it. However, we still believe in some form of advocacy for these individuals.

A third point we looked at is that it's difficult for us to form an opinion on this because the legislation as it stands has not been around very long. How do you judge the legislation that's been brought forward if you haven't had a chance to test it fully? That was just something we wanted to put forward to you.

A fourth issue that has been raised before but that we want to raise again is that it appears as though this legislation would decrease the accountability of the substitute decision-makers, in an effort to streamline the process. Combined with the increased definition of "family," and the individual nature of a lot of the people we represent, it looks as though this would be open to further abuse by individuals.

I can give you a specific example. Oftentimes when a family finds out that their loving son or daughter is sick with HIV, what ends up happening is that the family, the mother, the brother, swoops down upon them and takes over all of the control of their health care, of their finances, and basically shuts out of the picture distraught individuals who are their preferred individuals or their partners. You've got to take that into account in terms of the particular aspect we're looking at.

Removing the rights advice has probably been addressed by a number of people at this committee, but we would like to reiterate that declaring an individual incapable of managing their own affairs does not go far enough; you have to also inform them that they have the right to appeal. I probably need say no more than that. It is contained in our brief.



To reiterate what the previous party said about the plan of treatment, we feel that goes too far in terms of consent. We feel that informed consent should be on an activity-by-activity basis. This doesn't mean you have to have a piece of paper signed every time the person wants to go to the washroom. In general, the person is cognizant. They can still do the motor functions. They should be asked whether they want to eat, whether they want to go to the washroom.

We also came across a very interesting point in terms of plan of treatment which encompassed allowing for different settings. To us, this raised a political question in terms of the health care cutbacks and the fact that the pressure is on the doctors in the hospitals to get individuals out of the beds they are occupying and into other facilities. Is there, therefore, a conflict of interest to these individuals, getting them into, say, a palliative unit? We've had instances where individuals have been moved out of hospitals into palliative units when they wanted to go home and die rather than ending up in Riverdale Hospital. That is a definite problem as far as we see it.

We went through a number of statutory considerations, and they start on page 6. I probably can leave you to look at them yourselves, but I would just reiterate that we've outlined the definition of "family." Oftentimes in terms of gay males or intravenous drug users, the person doesn't necessarily live with their partner but they may have an intimate relationship. That should be an "and/or" rather than an "and."

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The right of refusal of assessment: The right of refusal of the incapacity assessment is very important, the expression of wishes, the consent to treatment and what treatment entails. It would also seem that under section 12 there was—I almost thought it was a typographical error, because at the end of the first line, if you read that correctly, "one health practitioner may,"—and if you skip down to clause (c)—"ensure that a consent is obtained in accordance with this act...." I would suggest to the committee that it should be "shall" rather than "may," because I think you should definitely inform the individuals that has occurred.

There is the consent to different settings.

Then I would draw your attention to the purpose of the act, on page 7 of our brief, which sets out the philosophical emphasis. If you're going to look at this legislation really to see whether it's providing for the individuals, doing what it's supposed to do, then I would draw your attention to clause (c). It says "to enhance the autonomy" of the individuals that it affects. It doesn't say "to support," it doesn't say "to aid," it says "to enhance." In our case in particular, people living with HIV and AIDS need that enhancement. They're vulnerable. They can't speak for themselves.

I don't know whether you're familiar with a nasty little progression of HIV and AIDS which is called CMV. It makes you unable to speak or make yourself aware, but you are fully cognizant of what's going on. Wouldn't that be a perfect, perfect scenario for somebody who has the right to make themselves known, and yet they've got a health care practitioner who says, "No, I think I know

what's right for them." There's got to be some third-party advocacy in terms of what we're thinking.

We can go through this in the liability sections and the definition of "evaluator." Although I haven't been here for all of the hearings, I suggest to you they've probably been looked at.

I would just like to draw your attention to the conclusions. I'll read them so that they're on the record. We would like to stress the following concerns:

(1) The rights which are expressed in Bill 19, such as the right to appeal an assessment, appear to be empty because there are no explicit mechanisms that direct a person who is in this compromised situation.

(2) The inherent makeup of the affected community and the fact that almost all of those living with HIV and AIDS will encounter health issues provide you with the increased credibility to our concerns over and above any general concerns of the system.

All of the affected community is going to come in contact with this. If you were aware of the number of people in our community who are scrambling to figure out what is a continuing power of attorney for personal care, what is a continuing power of attorney for finances, what is a living will. We deal with it every day. We've been open only seven weeks.

(3) The decreased level of accountability raises the spectre of increased abuse of those who are no longer able to advocate for themselves. We have seen this happen all too often in the past and were hoping that legislation would develop towards greater, not lesser, accountability for those in positions of power over vulnerable people.

I'm talking about families in particular and parents who have been alienated by their sons or parents who've been alienated by their children.

(4) The amendments to these statutes are obviously a shift backwards to place power in the hands of those who traditionally held power over vulnerable people. Health concerns of the person and the development of individual rights and freedoms are not a priority for those who have proposed the bill if you look at it from the perspective of where it was coming from.

(5) Primarily, we view the amendments as an attack on the autonomy of the people in our affected communities, and they're contrary to the principles stated at the beginning in our mandate as a legal clinic serving the community.

That's a brief analysis of where we stand. We are the first of probably two or three other groups in the affected community who are going to be presenting to you, and so by way of introduction I suppose that would suffice and we open questions to any of you.

**The Vice-Chair:** Thank you, Mr Cowan. I appreciate the presentation. We're going to move to questions now. We'll be allotting about five minutes per caucus. The Liberal caucus I have down here as being first, but since none of them is here we'll turn to the NDP caucus and Ms Boyd.

**Mrs Boyd:** Thank you very much for your presentation. The issue you raise in terms of definition of "family" is an ongoing one and one which obviously we haven't been able to get a solution to that would have

been amenable to your particular community. One of the things you should know is that when the news about the changes in this act first came out, there was a great deal of fear that the emphasis on the priority of family and swinging responsibility back to family, which was the way in which the press releases all read, led all of us to fear that those who had given a power of attorney to someone of their choice who was not a family member might lose that ability to choose.

That, of course, now that we've all seen the bill, is not the case, but what it does do is put the onus on people in your community in particular, at a time when they're feeling particularly vulnerable and anxious about themselves, to sign those powers of attorney, to understand what they mean and to put the conditions in in a way that is going to be binding. I know how difficult that is when someone has received a diagnosis that in effect is at best very serious and at worst life threatening, but that protection is there.

Can you tell me how difficult it is to persuade people within the community that it is absolutely essential for them to make their wishes known ahead of time before incapacity sets in?

**Mr Cowan:** I suppose in terms of a disease, it hasn't been around as long as a variety of other ailments. However, I would indicate to all the members of the committee that the community is a lot more mobilized than it used to be and far too often—and I'm not saying one in 10, I'm not saying two in 10, I'm saying probably three or four in 10—the family interferes in the wishes of the individual. That's why we're really adamant that they have to go forward with these.

On a more grass-roots level, we've had individuals who've actually taken duly executed powers of attorney to the banks and the banks have not recognized them. There's a problem just with the whole concept itself within the confines of the disease. Yes, they are moving forward, yes, they are aware that it's important to do that, but I don't think the safeguards built into this amended legislation are adequate.

**Mrs Boyd:** Part of the educational task is not just educating individuals themselves that they need to be signing these powers of attorney, but really is an education of the whole community that they take precedence over someone who comes and says, "Listen, I'm so-and-so's mother and therefore I have authority."

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**Mr Alex Brooks:** I'd like to say something as well. The only way in which somebody who is very close to an individual, who has been involved in their decisions but might not fit the definition of "partner," the only opportunity that individual has is through the courts and through an application to override any of the other people who might be on the list.

For this particular community, that creates an adverse effect on the community in terms of security if they have no executed powers of attorney. If they have executed powers of attorney, yes, it's very easy to convince, but it puts a heavier onus on this group of people both in terms of their requirement to have all the legal documents in place, but also in terms of the survivors or the people who are helping them; it puts a greater onus on them in terms of their access to process.

That's what we're trying to get at, that there are still a number of people who do not, will not, and never will draw up powers of attorney, because they are expecting their loved ones who are their people around them to help them, and sometimes the legislation will not allow that to happen without a lengthy court process.

**Mrs Boyd:** And even then.

**Mr Brooks:** Yes, and even then.

**The Vice-Chair:** Thank you, Mrs Boyd. We're going to move now to the Liberal caucus. I know you may have questions. You have five minutes.

**Mrs Caplan:** I've had an opportunity to briefly take a look at your submission. I apologize that I wasn't here when you read it into the record. I was called to the phone. You raise concerns that have been raised by others as well. The one I would like to focus on is the one that you raised around the need for education and understanding of what this means. I held several forums in my riding under the old act, and I was amazed at how many people did not understand even the most basic of what exists today, or before the former legislation, as far as the ability to execute a power of attorney for their financial decisions, and of course the concept of a power of attorney for health decisions was a new one.

I believe the government has a responsibility to see that unbiased information is given to professionals who will have questions, to families, to consumers and to patients. I put consumers and patients together because you're a consumer today and tomorrow you may be a patient, someone who accesses it. So it's those three categories.

I believe that the Consent and Capacity Review Board, while it is a tribunal, has the information of how the law is being interpreted and also can offer education, as they do now, in a very limited way. What I find is that people don't like to hear the information directly from the government. Do you agree with that, and that we should be looking for a neutral body with expertise in this field which will give unbiased and impartial information on how the act is working and could also, then, seek advice from affected groups within those three categories?

**Mr Brooks:** That would be certainly preferable to having a government body try to pass on the information. The situations that we encounter where institutions generally are not even obeying properly executed powers of attorney, that's very distressing. I don't know. I don't know who you call. We just went in and said, "I'm sorry, you have to do this; otherwise you're breaking the law," and that usually helped out. I would like to see that, an independent body which can provide the consultations required for health care professionals to be up.

We had a situation where a health care professional thought that the definition of "partner" was the same as the old family law definition of "spouse." So the person who was claiming the right to make decisions was not actually recognized by the health care practitioner. It was a matter of actually telling the person that it was okay to accept instruction from this person because he is actually a partner.

**Mrs Caplan:** One of the things that came up in the forums was the issue of taking a power of attorney into a bank and having them say, "Well, it's not in our form,



and we won't accept that." The message was very, very clear, and I think people have to hear this, and it's perhaps good to get it on the record here, and I know that the office of the public guardian and trustee will not mind if anybody phones their general number. If you're at the bank and they say, "We're not going to accept this," you say, "Let's phone this office." In fact, I think their phone number should be listed on the form in the kit; I know it's in the instruction book. They will say: "Yes, you must accept that. It is the law." So that's an easy way to get information on the acceptability of a duly executed power of attorney.

The issues that flow from that, particularly the ones under the Consent to Treatment Act and the enforcement of the directives of that power of attorney, are much more complex than I think anyone realizes, and you've just raised one of them. That's where education of not only the institutions but the providers in those institutions is extremely important. We heard from presenters who said we need time to do that. So I hope the government will hear that. This legislation does not give the mandate to anyone to provide that education. I hope they'll give that mandate to the Consent and Capacity Review Board because of the fact that they're doing some of it already and that it would be easy, with very limited resources, to expand some of that activity, because right now they deal primarily with providers and families.

**Mr Cowan:** Just to follow that up, across my desk about two weeks ago came a book about three quarters of an inch thick that was the handbook for physicians on the Consent to Treatment Act and the Substitute Decisions Act. I don't know whether you've seen it. I looked through it as a lawyer and thought there is no practitioner who is going to read this. It's got to be simplified. It's got to be streamlined. I agree with that in terms of where it's going, but there have to be some basic rights also that are maintained within the context of the legislation.

**Mrs Caplan:** And there has to be a place that you can call to get a question answered.

**The Vice-Chair:** Mrs Caplan, I'm sorry, I'm going to have to cut you off there. We're going to move to the government side now for five minutes of questions.

**Mrs Johns:** I just wanted to draw to your attention a section about the substitute decision-maker and see if this somewhat alleviated your problem or not—the problem of someone who cares very much for a person who's not family being able to act for them in times when they need it. Under the substitute decision-making act, any person who is over 16 can apply to the Consent and Capacity Review Board to be able to be appointed as the representative of the person at any time after they become incapable, and in fact the incapable person can even apply to that board and say, "I wish to have this person appointed." Does that help in any way with the problem you're talking about, family overriding friends who may be a better appointee?

**Mr Cowan:** Marginally yes, but I would suggest to you that the preferred individual, as we're calling them today, shouldn't have to apply to any board to gain status, that it should come somewhere within that pecking order, so to speak. They should be allowed to have just general standing in terms of somebody who is interested

in the care of the individual. That doesn't have to be a lifelong friend. We've got people who just have nobody except for one friend who wants to be around till the end. Oftentimes these aren't sophisticated individuals. They don't have a lot of money for legal representation. They don't know the process of applying to a capacity board. All they know is that their friend has expressed an interest that they would provide some direction as to their health care or their finances in their terminal days. Allowing them the status within the legislation itself is what we're going forward with.

**Mr Clement:** I just wanted to follow through on that. That's the area of your presentation I wanted to focus in on as well because you've said in your brief that the way to deal with that issue—and there's no question this is the archetypal area where this is going to come up, and I'm sure it is a time of high emotion and anxiety, and then you've got perhaps family members who feel the people the afflicted person is choosing as his or her friends are exactly the people who got them into the mess in the first place. I can just imagine the types of arguments that are used in that case. I'm sure it's very difficult to sort out hierarchies and so on.

Getting to solutions, though, you say the solution is to expand the definition of "partner." That's what you say in the brief. I just want to probe that a bit because I'm fearful that if we expand the definition of "partner" too much it renders the definition meaningless in terms of an assisting tool in situations like this. Is there anything else that you considered that would get us to the goal where we want to get to on this?

**Mr Brooks:** I think the primary concern there is that we already don't really require all that much of families. We just want them to be there and to somehow have some of the similar structures of DNA, and that's all they are required to have. I think it's much more important for there to be some general system of vetting anybody who was going to be assuming the substitute decision role and that simply because the individual, through their life process, has been alienated from their family, or perhaps doesn't have family in this part of the world, or who has not established any kind of lifelong relationships that would fit the definition of "partner"—that that person should be excluded from having someone who truly loves them who doesn't fit the definition of "partner" to be able to make those decisions for them. So it's both sides of it.

**1630**

The level of accountability in this bill is severely lower than what we would prefer in terms of being able to—you don't even have to make a statement that you have any connection with the individual if you're a family member. The whole idea I think is just to loosen that up to the point where you are not required to have a family if you don't have the luxury of family, and if you don't have the luxury of family you shouldn't have to go through a court process to get guardianship. You shouldn't have to go through a court process to get the ability to make that decision.

It's difficult. I think you'll hear from other groups. AIDS Action Now, Kingston AIDS Project and a few other AIDS groups are going to be presenting. Ask that question of them as well because—

**Mr Clement:** I'm just wondering whether the solution is—when you try to carve things out in legislation you have to paint with broad brush strokes, as you know, and it seems to me that this is a case where individual circumstances must, of necessity, be part of the solution. I'm wondering whether we're kind of missing the boat trying to fix the legislation when in fact we should be emphasizing a case-by-case understanding and sensitivity.

**Mr Cowan:** I think probably you're right in case by case. It's very easy for us to sit here in downtown Toronto where the prevalence of this disease or this condition is a lot higher than elsewhere, but put yourself into a smaller community where there is only one case and you don't have the support and you don't have the people who are aware of the disease.

I'd also like to raise the issue of families that come into the picture near the end and they have absolutely no knowledge whatsoever of the health concerns of the individual. I've seen it happen where families have come in and absolutely turned the process upside down because the preferred individual's rights as the spokesperson or the substitute decision-maker are not entrenched.

**The Vice-Chair:** Thank you very much. I want to apologize. We are out of time. I want to thank both of you, on behalf of the committee, for your presentation.

#### ONTARIO MIDWIFERY CONSUMER NETWORK

**The Vice-Chair:** The next presentation will be by Yvonne Osondu and Sasha Padron from the Ontario Midwifery Consumer Network. Good afternoon. You'll have 30 minutes for your presentation and you may want to allot some time at the end for some questions. You can begin any time.

**Ms Yvonne Osondu:** As you can see, I have my little baby with me. If he does get a little fussy I will just take him out and give him what he needs and come back. My name is Yvonne Osondu and this is Sasha Padron, and we are members of the Ontario Midwifery Consumer Network.

We're thankful for the opportunity to comment on Bill 19. We would like to discuss an important issue specific to the Consent to Treatment Act. We are here today on behalf of the membership of the Ontario Midwifery Consumer Network, also known as the OMCN, to share a deep concern around the exemption of the administration of eye prophylaxis ointment to the newborn from this act. This exemption drastically affects consumers of maternity and newborn care, but more dramatically consumers of midwifery care.

Our organization was founded in 1983 by a group of consumers and health care professionals who saw midwifery care as a safe, desirable, cost-effective option for child-bearing women and thus joined together to help towards the acceptance of midwifery into the health care system. Over the past decade we have represented thousands of families from Rainy River to Ottawa to Windsor.

**Ms Sasha Padron:** We've worked cooperatively with the governments over the past 12 years, with members of all political parties. We've been thrilled to find all-party support for the implementation of midwifery in Ontario.

Our goal was realized on December 31, 1993, with the proclamation of the Regulated Health Professions Act and the Midwifery Act.

Along with participating in the implementation and standardization of midwifery care, we've worked hand in hand with midwives in the creation of their model of care and their scope of practice. We continue to be actively involved in the regulation of the profession by sitting on committees of the College of Midwives of Ontario, the Ministry of Health and the midwifery funding agency.

As consumers, we bring attention to any legislation which may change the model of care. The exemption of administering the eye prophylaxis ointment from the Consent to Treatment Act puts the midwife directly in conflict with her profession's philosophy of practice, with her model of care and with her client.

Prior to the proclamation of the Midwifery Act, midwives voluntarily informed their clients about procedures affecting their care. Both midwives and the families that chose to use their services felt that informed choice was an integral part of midwifery care and therefore integrated informed choice as one of the six critical principles of the model of midwifery care.

Through legislation and the regulation of midwifery care, midwives are now required to adhere to the model of care. By not providing informed choice, a midwife is in violation of the philosophy of midwifery care and the model of midwifery practice. As consumers, we seek out the services of midwives precisely because they respond to our expectations of the care we should receive during childbearing.

When we take on midwifery care, we make a commitment to actively participate in making decisions and choices affecting our care. The midwife is equally responsible for facilitating the passing on of all necessary information in order for us to do so. This means being well informed and scheduling long clinical visits in which she is able to thoroughly inform and respond to questions and concerns. Integral to this exchange is the establishment of a relationship based on trust and respect. Consequently, midwifery consumers feel extremely close to their caregivers as their care progresses. For a midwife to suddenly breach this loyalty by not getting consent from her client before administering the eye prophylaxis ointment, that would completely undermine her model of care.

We're here today to formally request that the administration of eye prophylaxis ointment to the newborn be included in the Consent to Treatment Act in order to preserve the Ontario model of midwifery care.

**The Vice-Chair:** Is that the end of your presentation?

**Ms Padron:** Yes.

**The Vice-Chair:** We'll entertain some questions now and start with the NDP caucus.

**Mrs Boyd:** I have to confess my ignorance here. I was not aware that this would be any different from the administration of any other kind of medication. Can you tell me what section of the act this is specifically taken out of?

**Ms Osondu:** If you see the Consent to Treatment Act, it says in the parts that are excluded from the act—

**Mrs Boyd:** It's one of those?



**Ms Osondu:** Yes, it is.

**Ms Padron:** Exactly. It's one of the items that are excluded.

**Mrs Boyd:** You're essentially saying that you don't want it excluded. Why would it be included? What is the argument that you've been given for its inclusion?

**Ms Osondu:** It allows for the midwife and the client to continue dialogue, where the midwives say, "These are the kinds of things that I have to do to you as a client," or in a medical situation it would be known as "patient," of midwifery care. Throughout the nine and some months that you're with a midwife, it's always this dialogue of they giving you the information; you, the consumer, making the choice. Suddenly your baby's here, they're doing something to your baby and you cannot say, "No, I do not want it."

**Mrs Boyd:** I guess I asked the question the wrong way. Why is the government requiring midwives to do this? What is the explanation?

**Ms Padron:** That's what we're unclear about. Obviously, all other procedures are included in the Consent to Treatment Act but there are a few things that have been exempted from that.

**Mrs Boyd:** Is that specifically because there is a health problem that is prevalent enough that it's considered to be in the public interest?

**Ms Osondu:** Well, 100% of babies are given the eye drops, whether they have the baby at home or in the hospital or in a clinic. The eye drops are to prevent infection that the baby may contact on its way through the birth canal. The two infections that are considered here are chlamydia and gonorrhoea.

1640

**Mrs Boyd:** Why would the midwife not all along have explained to her client that this is a requirement of the law and that this will happen and it's just part of the procedure?

**Ms Osondu:** I'll explain it to you this way. When you go to a midwife or a physician for prenatal care, there are a number of tests that a doctor would do routinely. One would be an ultrasound. In doing your health history, doctors would give you a reason why they would need to do an ultrasound, and so would midwives. Doctors do it routinely; midwives give the information to the women and they decide whether they want it or not, given the pros and cons of this technology and the reason for wanting this test. Based on the woman's history and the woman's knowledge of her health, she can then decide that she doesn't want to do this.

The same, we think, would go for the eye ointment. The woman knows her history; she could then decide whether or not this is something that her baby would be at risk for. However, because it's not included under the Consent to Treatment Act, a midwife doesn't even raise this as an issue for the woman. She just says, "I am going to administer this drug."

**Mrs Boyd:** But as with things like immunization, for example, that are required—we require very few medical procedures, immunization being one of them and this being another because of the widespread danger to children who are at risk of complications—do you really

believe that women would be refusing this if they had the choice?

**Ms Padron:** What happens is that it doesn't even allow for that to occur. What we're concerned about is that by exempting it from the law, it's completely taking away the opportunity for informed choice in that scenario. All through your care, this is the type of dialogue that has been going on and it's an essential part of the care, that at every step of the way you have had open dialogue about every single procedure that is out there and available and that you can choose and decide on.

Now suddenly there is a procedure that this principle of informed choice is taken away from you so that the midwife is committed, has to perform that procedure without discussing it with the woman, without informing her about it, without giving her the opportunity to choose to do it or not to do it. That's our concern, that it's in direct conflict with what midwifery care is all about. In terms of requirement, from what we know there's been enough research to show us that it doesn't make sense that there isn't enough grounded reason for it to be a requirement, that there still is room for a patient or a client to make that choice on her own.

**Ms Osondu:** Further to that, users of midwifery care have said no to this prior to midwifery being a legislated profession, that they didn't see a reason why they should administer this ointment.

**The Vice-Chair:** I'm sorry, Ms Boyd, we have to move on. I move to the government side. You have eight minutes.

**Mrs Johns:** I just want to try and put some understanding to what's happened and then let you comment on that.

It was part of the Consent to Treatment Act that this would be a process that would happen, and then with the regulations under the previous government, they eliminated this as a treatment, so they said that this is not a treatment.

I think all three parties believe here, and government as a whole believes, that this is an issue of public health, that babies should have this ointment in their eyes and that really, if a parent chose not to do that, it would not be in the interests of the child. So we feel that it's an issue of public health, it's regulated under the HPPA that 1% silver nitrate solution has to go in the eyes of babies within one year—

**Ms Osondu:** One hour.

**Mrs Johns:** One hour, I'm sorry.

**Ms Osondu:** It's erythromycin; it's not silver nitrate any more.

**Mrs Johns:** Okay. My thing says that. We have talked with Dr Schabas, who is the public health representative with the government, and he still believes that this is a public health issue, that every child should have this within one hour. That's why it's come out of the consent act and has become part of the Public Health Act, because we believe that it's a very important aspect to a child's future and his or her development.

Is there something that you have a problem with in what I've just said or something you disagree with in Dr Schabas's approach, that this is a public health issue and every child should have it?

**Ms Osondu:** We're still saying that the choice should be with the parents. If a parent is fully aware of her medical history, then she should be given the choice whether or not she wants these drops administered to her baby. We're assuming, when you administer the eye drops, that the woman has an STD: gonorrhoea or chlamydia.

**Mrs Johns:** Is it not better to err on the side of protecting the child, if it does the child no harm, to have this in his or her eyes in the first hour?

**Ms Osondu:** Or would it be better to screen the woman in pregnancy for chlamydia and gonorrhoea and treat her then?

**Mrs Johns:** Okay. I have no other questions.

**Ms Padron:** Do we still have time to comment?

**Mrs Johns:** Does anybody want to comment any more?

**The Vice-Chair:** Any more questions on the government side? You do have a few—

**Mrs Johns:** Do you want to add something to that? I'm sorry.

**The Vice-Chair:** Go ahead.

**Ms Padron:** Yes. I see exactly what you're saying, and it's not that we disagree that it's a public issue. It's just that there are various other things that are also really important, like the vitamin K injection that's given to babies and various other procedures that happen because there is an interest for mother and baby. That's not what we're arguing.

What we're feeling is that it's taking away that exchange of informed choice, where the parent is able to make that choice. Many will choose to do it, some may choose not to, but it's happened within the framework of informed choice.

**Mrs Johns:** I see what you're saying. I just worry about the child's safety.

**The Vice-Chair:** We're going to move on to a quick question from Mr Parker. You do have about a minute left.

**Mr Parker:** I just want to follow along on the same point. I think the difficulty that we have between us is this: As a government we rely on the advice of people who are experienced in the field, and the experience of the western world is that there are certain treatments that are vital in maintaining public health at various stages of a child's upbringing. It's beyond question whether it's good or bad or desirable or undesirable; it's highly desirable.

It's very cumbersome to have to explain that to each person, one by one by one, each time the issue arises, particularly at the time of birth. The clear experience is that it is very important and very valuable to administer this treatment within one hour of birth. There's not a lot of time to do a lot of talking at that point and try to explain this to a mother and get the consent and so on, and it's a treatment that is without risk.

That's what's motivating the provision in the statute here. I wonder how we can reconcile that against your wish that the mother in each case be given the chance to make the decision when you've only got an hour to work with and there's clear evidence that it's desirable. If we followed your approach, we'd run the risk that many

mothers would be confused and wouldn't recognize the importance and would probably opt to say no, because that's the inclination when you're not really sure of yourself, and all these babies would be put at risk. Should we as legislators put newborn babies at that risk?

**Ms Padron:** Do you want to answer, Yvonne?

**Ms Osondu:** We're not at all suggesting that by giving women the information to make a choice would put their babies at risk. If a woman knows that she's got chlamydia or gonorrhoea, then she's not going to say, "No, I don't want you to put this ointment in my baby's eyes that will prevent an eye infection that could be damageable." But if a woman knows her sexual history and knows that she does not have these diseases, then it doesn't make sense for her to put the ointment in their eye, because it would be for what reason? We're just saying, please give the women the information so that they could make the choice that is best for them and their baby.

**1650**

**The Vice-Chair:** Mr Parker, we're going to move on. I'm sorry. We want to move on now to the Liberal caucus and Mrs Caplan.

**Mrs Caplan:** This is not a new issue, and in fact there has not been a time I think in the last couple of decades—and I think the ministry can confirm this, it has been standard practice over many, many years that first it was silver nitrate and now it's drops, erythromycin, and that has been standard practice because it is something that, as you said, is prophylactic, it protects babies. I believe, and as someone who gave birth to four children, that it is part of the standards of practice, whether it is the obstetrician or the family doctor or the midwife who's doing the delivery, to explain the benefits of this procedure and that that communication is extremely important so that the mother and the father, the family of the child, understand why this is being done. It is no risk.

The concern that I have if you were to change what has been the practice to allow this to become an issue of voluntary compliance is you would stigmatize those people who might be at risk for chlamydia or gonorrhoea and by that place children at risk, and that that's the reason why this is not a screening, this is a broad treatment, just as society has also chosen in other areas to demand vaccination before entry into school.

So this is an issue that I think midwives will continue to do an excellent role in communicating to their patients why it is important, but I do not support the option of being able to have a parent not consent on behalf of their child who would benefit from having this and where the mother, because of fear of being stigmatized, might choose to not have this if she would have to admit that those diseases were even possible.

I don't think you're going to find any support around this table for your request and I don't think it will interfere with the practice of midwifery in any way nor will it interfere with the need for the moms to be fully apprised of what is going on, but the reality is those babies are incapable of making the decision for themselves. What this legislation is about is who protects those who cannot make decisions for themselves, and society has decided that those prophylactic eyedrops are



in the interests of the child and I think that is in the interests of society.

**The Vice-Chair:** Did you want to respond?

**Ms Padron:** Okay, thanks. I appreciate that very much and it's understandable in the context of the model of care that you're discussing because of the fact, exactly as you were saying, that there's very little time, there's very little opportunity at that stage of birth to explain fully the whole process. I can see where that comes from.

Where we're coming from is a very different model of care where, because the midwife spends so much time with the client, that situation does not happen. She actually does have plenty of time and plenty of opportunity to explain that procedure.

**Mrs Caplan:** Maybe I wasn't clear. Let me try again. I think there are many family doctors and obstetricians who take the time during the visits over the nine-month gestation to explain what is going to happen on birth. Mine did, and I was aware that the eyedrops were going to be given to protect my baby's eyes and that it was not an issue of whether I consented to that or not. It was a public health issue that that was in the best interests of the child. There was no risk whatever to the baby. I think that that is part of the standards of practice. If it's not being done, if that explanation is not being given until after the birth, then I think that there's a question of the conduct of the practitioner, whether it be an obstetrician, whether it be a family doctor or whether it be a midwife.

The issue here is, should the mother be able to decide not to have this treatment, and as a public health issue we have decided collectively on the advice of the chief medical officer of health—and I say this to you as a former Minister of Health—that it is in the public interest for those babies, for all babies, to have the eyedrops. I personally believe that it would stigmatize the moms if they felt that by saying, "Yes, you can have it," that now they were suggesting that they might be subject to those diseases and therefore babies would be deprived of that treatment and place them at risk.

I'm looking around the table and everyone is nodding. I think they agree that it's in the public interest for the babies to have the drops. It's not a question of interfering with your model of giving care; we all support that. We know midwives spend more time, but I think most moms are given that information long before the delivery. I hope they are. They should be.

**The Vice-Chair:** If you want to have a quick response, you may, and then we're going to have to wrap it up. Do you want to come up to the microphone, please.

**Ms Osondu:** It just seemed shortsighted to wait for a baby to be born, give them the eyedrops, whether or not that mother has got chlamydia or gonorrhoea, and find out only once the baby's born, rather than screening all women during pregnancy for chlamydia or gonorrhoea.

**Mrs Caplan:** That's a separate issue.

**Ms Osondu:** Yes, but it is the reason why the babies are getting the eyedrops, to prevent an infection that's caused by these two.

**Mrs Caplan:** On that one—

**The Vice-Chair:** Ms Caplan, I'm sorry. I want to thank both of you for the presentation, but we're going to have to move on. Thank you very much.

The next presentation will be Dr Bill Sullivan, for the Saint Joseph Moscati Toronto Catholic Doctors' Guild.

**Mrs Johns:** Mr Vice-Chair, while he's coming up I just wanted to put on record that the Ministry of Health is supplying the first of Mrs Caplan's requests, which is regarding reviews of incapacity, admission and substitute decision-makers. They're going to be passed out by the clerk.

**The Vice-Chair:** Thank you.

#### SAINT JOSEPH MOSCATI TORONTO CATHOLIC DOCTORS' GUILD

**The Vice-Chair:** Dr Sullivan, welcome. You'll have 30 minutes for your presentation and you may want to leave some time for questions from the committee. You can begin any time.

**Dr William Sullivan:** I want to introduce myself. My name's William Sullivan and with me today is Dr Dan Fleming. And we have a paediatrician colleague who is busy with some emergency but he hopes to come. His name is Luigi Castagna.

The three of us are representing the Saint Joseph Moscati Toronto Catholic Doctors' Guild. Our guild was established in 1977 to promote Catholic values in health care by emphasizing in our work the fundamental dignity and interdependence of all humans regardless of life stage, illness or disability. The Toronto guild, one of three such guilds in Ontario, has approximately 400 members who are affiliated with both Catholic and public health care settings and involved in a wide variety of medical and dental specialties.

We thank the committee for inviting us to speak on Bill 19. Of the three acts revised by Bill 19, we intend to restrict our comments to the proposed Health Care Consent Act.

In general, we support the objectives of the act as outlined in section 1, but we wish to highlight for the committee three key issues not expressly addressed in the act, whose omission we judge to have negative practical and moral implications for health care in Ontario. Specifically, we draw the committee's attention to (1) the act's exclusion of direction on where health care professionals should now seek guidance and support for making responsible assessments of capacity, (2) the act's failure to clarify the meaning and legal status of the notion of "wishes" as previously expressed in a written document when a person was capable of expressing his or her wishes or general values regarding their health care, and (3) the act's omission of any attention to the vulnerability not only of patients but also those on the health care team who function as advocates for them.

#### 1700

**The determination of capacity:** The determination of a person's capacity to consent is a complex task requiring adequate preparation and support and a sensitivity to broader than medical concerns. This is particularly true in assessments of the capacity of children and individuals who have a cognitive, communicative or emotional impairment. It hardly needs to be pointed out that health professionals are rarely prepared for this complex task by their medical training.

Let us illustrate some of the complexities involved in assessing capacity. Consider the case involving the Clemens family that was discussed in the Legislature when Bill 19 was introduced. The Clemenses' son had a developmental disability, as well as recurring episodes of constipation. Unfortunately, he also had a tremendous fear of doctors and hospitals. In a visit to an emergency department of a hospital, he declined the proposed treatment for constipation. Under the Consent to Treatment Act, which had then just come into effect, the attending physician found the Clemenses' son capable of refusing treatment, despite his parents' vigorous insistence to the contrary. The treatment was withheld until a senior physician authorized it. By then it was too late; the young man had died of heart failure.

This case is often cited to support changes to the Consent to Treatment Act, which some critics have found to be too bureaucratic and rigid in its approach to procuring consent for treatment. The government has revised this legislation by including a provision that facilitates emergency treatments of persons with a disability—in section 23—and excluding, among other things, the detailed guidelines on how health professionals should determine capacity to consent and the rights advice process.

The Clemens tragedy illustrates the dangers of a too literal and mechanical application of the guidelines for determining capacity contained in the Consent to Treatment Act without due consideration of other relevant factors: for instance, the input of family and an understanding of developmental disability. Still, it seems to us that guidelines of some sort are necessary to ensure that assessments of capacity made by health professionals are not purely arbitrary and can be evaluated objectively.

The proposed Health Care Consent Act is silent about the need for any guidelines to regulate determinations of capacity and so effectively leaves such determinations entirely to the judgement of health professionals. Moreover, the elimination of the rights advice process effectively frees health professionals from the obligation of informing patients of their rights in relation to a finding of incapacity. Both revisions conspire, we fear, to an undue reliance on the judgement of health professionals in an area for which they may not be prepared or have support.

The meaning and legal force of the notion of wishes: Let us begin by illustrating the problem of the legal definition of "wishes" by means of another case.

Mrs Smith is an elderly woman with a chronic lung condition, but is otherwise in good health and living in a retirement home. She gets the flu that is going around the hospital, which worsens her chest condition leading to respiratory failure, such that she is unable to communicate her wishes as regards treatment. When she arrives in the emergency department, her attending physician, Dr Jones, finds a note in her chart dated 1993 specifying simply "Do not resuscitate." Dr Jones interprets this note to mean that Mrs Smith would never wish respiratory supports by mechanical means—that is, a respirator—regardless of the circumstances. As it stands, Dr Jones predicts that with medical treatment and respiratory support for a period of no more than 24 hours she would

recover from this event. The question we will focus on is, what is the legal status of these wishes and does Mrs Smith's substitute decision-maker have any authority to override her previously expressed wishes?

Reading subsection 19(1) of the proposed Health Care Consent Act, Dr Jones wonders whether Mrs Smith's substitute decision-maker would contravene her prior expressed wishes in consenting to his proposed treatment; that is, a period of respiratory support. He is also aware that according to subsection 27(2), he is protected from liability should he decide to follow what he interprets to be Mrs Smith's wishes as expressed in the do-not-resuscitate order, even if it goes against her substitute decision-maker's judgement. What remains unclear, however, given his reading of section 24, which forbids him from administering an emergency treatment defined in section 23 that Mrs Smith has previously refused, is his legal status should he take the other course of action, namely complying with the decision of Mrs Smith's substitute decision-maker.

What we hope to highlight for the committee is the problematic nature of prior expressed wishes when one is faced with a medically nuanced circumstance. The matter is not only one of defining wishes but also of distinguishing between wishes as generally held expressions of personal values—the intent, we take, of the act—and wishes as regards specific medical means to treat a particular medical condition.

In the above case, neither Mrs Smith, her substitute decision-maker, nor Dr Jones ought to feel, we believe, legally constrained to employ or reject certain specific medical treatments. On the other hand, these decisions should be consistent with a reasonable interpretation of her generally held values as she sought to express them in the do-not-resuscitate order.

Protection of the integrity of health professionals: Our final suggestion is that the act needs to protect the integrity of health professionals as well as patients. The therapeutic relationship involves two parties. We need to ensure that the act's concern to respect the decisions of patients or substitutes about treatment or withdrawal of treatment is balanced by a concern to protect the moral integrity of health professionals who cannot on legitimate religious or philosophical grounds carry out those decisions. Often these questions about conscientious objection arise with respect not only to individual clinicians but also to vulnerable members within a health care team. The committee needs to examine more closely the implications of the proposed act for such teams.

Consider, for instance, the particular vulnerability to which surgical nurses can be exposed. Mrs Smith is a nurse who works in a teaching hospital that is on the forefront of research on surgical approaches to treating gynaecological cancers. In her role as a surgical nurse, she cares for women with life-threatening cancers who have been persuaded to consent to radical surgical procedures aimed at improving survival.

Mrs Smith is concerned, however, that because of the overriding and acute anxiety experienced by some of the women, their decision for surgery may have been made without full appreciation of the associated side-effects of this treatment. Hence, she is troubled by her own involve-



ment in the treatment team's compliance with the patient's decision. She discovers, moreover, that within the team there is resistance to her questioning the patient's capacity to consent. In fact, she is often subject to censure for being a troublemaker who is undermining the efficiency of the team. Not wanting to risk losing her job, Mrs Smith learns to do her job and ignore her feelings of unease.

The multidisciplinary team is increasingly a reality in hospitals and other medical settings. Section 12 of the proposed Health Care Consent Act makes provisions for one health practitioner to propose a treatment plan and to determine capacity for consent on behalf of other practitioners involved in the plan, but does not address the question of what happens when there is disagreement within the treatment team about such determinations. More importantly, there's no provision in the act that protects the moral integrity of persons who may disagree on legitimate religious and philosophical grounds to being involved in treatment or withdrawal of treatment to which a patient or her substitute consents.

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**Conclusions and recommendations:** We affirm the general thrust of the proposed Health Care Consent Act in that it strives to protect vulnerable individuals, to ensure that the treatment decisions of those who are capable of providing a consent are given due consideration and to provide for the necessary medical care of those who are incapable of providing such consent. However, we have highlighted three problematic areas in the formulation of the act to challenge this committee to reflect on the implications that may be unanticipated and, in our judgement, undesirable:

(1) A key practical issue in the medical setting is the complexity and effort involved in making responsible assessments of a patient's capacity for consent. Although the act retains the old legislation's definition of "capacity," it is silent on the more important issues of where health professionals should seek guidance and support for making responsible assessments of capacity, how to ensure consistent standards across health care settings, and what measures should be undertaken to inform patients and families of their rights of appeal. We are concerned that by failing to address these issues explicitly, the act places too much reliance on the judgements of individual clinicians in an area for which they may not have adequate preparation or support.

We recommend, therefore, that this act include a clear statement of the need for assessments of capacity to be accountable and to follow standard guidelines, if only to refer these considerations to the authority of regulated professional bodies.

(2) Another key practical issue, one that is becoming increasingly commonplace, is the legal status of written advance directives. We highlighted some concerns that health professionals have about being bound by wishes that are made in advance of the concrete circumstances that patients may encounter.

We recommend that you consider defining more clearly the meaning of "wishes" in the act to distinguish between generally held expressions of personal value and context-specific treatment decisions. We also encourage

the committee to take an explicit stance on the legal implications of a physician or substitute decision-maker's refusal to follow the wishes, in the sense of context-specific treatment decisions, of the patient, made when capable, when there is a sound reason to believe that she would make a different decision if capable and informed of the particular context of the treatment.

A final practical issue is the need to protect the freedom of conscience of health professionals. We sought to highlight the vulnerability of certain members of the health care team in virtue of their solidarity with vulnerable patients. This is an issue that may have been considered beyond the scope of this legislation, but we suggest that the long-term moral health of our system depends upon a systematic openness to being challenged by those within the system who raise moral concerns. We recommend, therefore, that you consider extending your concern to protect vulnerable patients by including some protection clause for those health care workers who advocate on their behalf.

Thank you very much.

**The Vice-Chair:** Thank you. We're going to move to questions now. We've got about five minutes per caucus and we'll start with the government side.

**Mrs Johns:** I just want to explore some of the different groups you were talking about. Thank you. Your presentation makes me think a lot and I appreciate that.

When we're talking about Mrs Smith here and her having probably an advance directive, which is what I think you're saying here, and it says "Do not resuscitate" on it, so the woman has decided that's what she wants to have happen, and nobody has any reason to believe that's not what she wants—I think that's what you're saying—are you suggesting that the substitute decision-maker or the health practitioner should be able to override her directive?

**Dr Sullivan:** I think the point was really philosophical and methodological, and the issue is that there is something inherently problematic about kind of general guidelines or specific guidelines that are made concerning medical matters in advance of any understanding of particular contexts wherein they may arise.

On the one hand, I guess the particular case illustrates that it may be a matter of interpreting a DNR order. The particular context I'm thinking of is one I'm very familiar with working in Sunnybrook hospital and having patients come into the emergency department with an order somewhere in the chart that's dated some time in the past that just says, "Do not resuscitate." The particular circumstance of the case was someone who has a reversible illness. When they made this directive, what they may have been wishing was not to be undergoing cardiopulmonary resuscitation—people pounding on their chest—when in fact the hope of survival was minimal. Perhaps that's one interpretation. The context may arise that this person needs a short period of respiratory support to overcome an acute illness. By definition, that is a form of cardiopulmonary resuscitation, providing respiratory support. So if you interpret her directive as something that is a medically specific treatment—that is, "Never do I want a resuscitator applied for any amount

of time"—then to be consistent with that directive, you would not treat.

**Mrs Johns:** But the substitute decision-maker in that case would most likely know if the wishes have changed, for example, or if it was in a specific situation and that situation has changed, and be able to change the directive as a result of knowing what the true wishes of the person were.

**Dr Sullivan:** Yes.

**Mrs Johns:** So, Mrs Smith, as long as her substitute decision-maker was doing the job, would probably get the results she wanted to from them. She should also have her advance directive more clearly outlined, but the results would be the same and would be the acceptable results you want to have happen out of this bill.

**Dr Sullivan:** I guess the concern that we tried to raise by the case was—well, assume that your scenario's true, that the substitute decision-maker does think that Mrs Jones—

**Mrs Johns:** Knows.

**Dr Sullivan:** Okay, knows that this is the case. The physician may well say: "Really, the expression here is pretty specific. The wishes seem to be no resuscitator. She's not getting a resuscitator."

**Mrs Johns:** But she's incapable and he has to go to a decision-maker.

**Dr Sullivan:** This is my question. According to the law as we read it, the advance directive takes precedence over the substitute decision-maker if she explicitly contradicts—

**Mrs Johns:** No. I'll find you the section in the act, but the section in the act says explicitly if it's a new directive or if someone knows of something that has changed after the advance directive has been done, they have the ability to go forward and to make that decision.

**Dr Sullivan:** Okay, granted, but I guess the main kind of methodological point is that with the whole advent of advance directives, of people expressing wishes, it calls into play interpretation. First of all, to make that helpful for practitioners, they have to understand some of the nuanced conditions that may arise. I would suggest that if you want to help clarify the issue for practitioners, one thing you could try to do is define "wishes" as something more general. That way, it may not tie down people to very specific medical decisions that are very context-dependent.

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**Mrs Johns:** There's a real danger there in the fact that if for some reason I don't want something to happen to me and I don't make that specific, then you can resuscitate me or something when I don't want to have any medical intrusion or whatever that might be. I think that you're walking a very fine line there. We have to respect people's wishes if we know them, and if they have changed, we have to respect the wishes that have come forward since then.

**Dr Sullivan:** Yes, okay. Right—

**The Vice-Chair:** I'm sorry, we're going to have to move on to the Liberal caucus. Mrs Caplan, you've got five minutes.

**Mrs Caplan:** Let me try to explore this further, because I think we're down an important path. It's my

understanding of the legislation—I ask the ministry to step in and correct me if I give any incorrect information, because this should be clear—that if I were to write in a power of attorney that under no circumstances did I want to be resuscitated, that would have to be respected should my heart stop and I arrest. Right? All heads nodding? If I signed a power of attorney and it said that if I go into cardiac arrest I do not want to be resuscitated, that would have to be respected, if I was that clear.

If, on the other hand, my power of attorney said, and it's an expression of my values and my beliefs, that I want to be treated for cure, that would have to be respected: "I don't want to be resuscitated unless there is better than a 50-50 chance of cure. To my substitute, you have to follow that direction." It's now at their discretion. But it's at the substitute's discretion, and in consultation, as a partner with the team, if the individual or his substitute is a member of the care team, then that decision is made as to my wishes, that I only wish to be resuscitated if there is a better than 50-50 chance of cure.

**Dr Sullivan:** Okay, but just to press the point a bit, the question was—

**Mrs Caplan:** Let me just finish the third point. The third point is, if it's unclear. If the doctor or the substitute decision-maker wonders whether or not the decision is being made in my best interests and following my wishes according to any advance directive that may be there, it's my understanding that either one could go to the capacity board for a ruling as to whether or not my wishes were being followed, and you'd have an impartial judge looking at the situation. I think that's correct. Yes, I've got a nod from the ministry people. Those are the three scenarios.

**Dr Sullivan:** In this particular case, though, that's not very practical. The fact of the matter is that this woman is in respiratory failure and you have to decide pretty quickly whether you're going to supply a means to help or sustain ventilation.

**Mrs Caplan:** I would suggest that your legal liability would not hold you safe from suit if you did not follow the instructions of the substitute.

**Dr Sullivan:** Okay, but it talks about "reasonable interpretation" of the advance directives. If my reasonable interpretation is that she does not want resuscitation and the substitute decision-maker is saying, "Well, yes, you should go ahead and do it," as I read the legislation, I would not be liable for prevailing.

**Mrs Caplan:** My view, as a lawmaker, is that you shouldn't try it, because if the substitute decision-maker says, "Resuscitate; that's not what her wishes were," you would not be protected from liability in that case.

**Dr Sullivan:** Right, okay. Just to back up a bit, I guess my point was not the particular legalities. That's not our field. It's the medical reality of making wishes in advance of medical circumstances and being unclear about what you're trying to express in those wishes. We agree that those wishes are important and we want them to be correctly interpreted. What we recommend is that you just be more clear that what is being expressed is something, in philosophical terms, a priori, some very general expression of one's values, and not something



that is a posteriori, that is, concrete, very bound up with the circumstances that may arise.

**Mrs Caplan:** I wish we lived in that kind of perfect world. Unfortunately, there's a whole lot left to individual judgements, and therefore if someone has—

**Dr Sullivan:** Judgements are concrete and empirical, though, and the wishes are general and abstract.

**Mrs Caplan:** That's true, but if I say, "This is the person that I leave as a substitute decision-maker," their wishes have to be respected, and if they guess wrong as to what I want and they pull the plug, so be it. I trust that person and I would hope the medical practitioners would listen to him or her.

**The Vice-Chair:** Ms Caplan, we're going to move on now. Mr Marchese, you're next.

**Mr Marchese:** I have two questions and I want to change gears a bit to the other point that you made with respect to capacity. You weren't questioning the definition of "capacity"; you say it is silent on the more important issues of where health professionals should seek guidance and support for making a responsible assessment of capacity and how to ensure consistent standards. I'm not sure whether you have suggestions as to where they might go to do this. That is the one question. The other is, could you have consistent standards as they relate to the issue of capacity, and would that be practical, useful, or could it bring about some negative consequences here or there?

**Dr Sullivan:** Maybe I'll defer to my colleague.

**Dr Luigi Castagna:** I'm speaking as a paediatrician, so my perspective is different from Dr Sullivan's. Generally, issues of resuscitation, of consent, have to do with persons who are in very good health and young, so the situation is quite different, but some of the things apply none the less.

I think what we are mostly concerned about as a Catholic guild of doctors is that there is some accountability among physicians in the process of decision-making and of establishing whether or not somebody is incapacitated.

These guidelines can be established at various levels. For example, they can be established at the level of hospital policy, and anyone who is declared incapacitated within an institution should meet certain criteria. The other level is part of the rules of professional conduct, professional ethics established by the college, so a physician is ethically obliged to follow certain guidelines. Finally, does legislation also have a role in reinforcing these guidelines in a very general way, maybe to set the climate in which physicians realize that this kind of decision is of great importance?

It's really a life-and-death decision sometimes. It's depriving somebody of his civil rights really. It should be taken with great care, and if the physician who is called upon to make a decision is not experienced, he should maybe defer it or consult with somebody else. Really it's a question of, would you think that legislation addressing these issues would establish a climate in which these issues are taken more in consideration than they are with the present proposal?

**Mrs Boyd:** It seems to me that in your presentation your real issue is around how to deal, first of all, with

how to determine whether a person has the capacity to make the decision, if they don't, then where the decision lies, and that it's almost always around the very ultimate kind of situation of life or death. Certainly the situations you've presented are that way.

It seems to me that the factor of allowing, by law, a patient now to have a role in making a forward decision is all it's exercising here. Doctors have always made these decisions and they've always made them according to their own moral precepts, whether to palliate or whether to treat, whether to resuscitate or whether not to. The whole purpose of this legislation is to say that doctors don't make those decisions alone any more; they make them with the patient, and if the patient is capable, the patient can do that directly. If the patient is not capable, then an advance directive or a substitute decision-maker makes that decision. So I think that part of the problem is really the moral dilemma that doctors face every day and always have and that this is just a complicating factor to it.

Our problem is that we as consumers of health care probably are not clear enough in giving our advance directives of what we want. In the case of your chronic lung condition, for example, if this is chronic obstructive lung disease and this person has been in respiratory failure before and has said, "I wish you didn't resuscitate me; put an order on and don't resuscitate me the next time," I think that's a pretty strong message, whether the flu caused the respiratory failure or whether they went into a respiratory arrest because of the low ceiling. Really, basically that's your problem.

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In the cancer situation, for example, a member of the team doesn't believe in the drastic treatment and would prefer to see palliative treatment, but the team is moving ahead with the thing and apparently has—it seems to me that what you're bringing to us is a very real example of the dilemma of helping people to express their needs. For example, a do-not-resuscitate order should probably say, "Do not resuscitate if this condition is irreversible, but if the condition is reversible, resuscitate to the point of living on a machine," or something. We should help people to be more precise and that's the educational factor that comes into play.

**The Vice-Chair:** I'm sorry. I'm going to have to cut you off there. We are out of time. On behalf of the committee, I want to thank all of you for your presentation.

## A-WAY EXPRESS

**The Vice-Chair:** Our next presenter will be Laurie Hall from A-WAY Express. Good afternoon, Ms Hall. You'll have 30 minutes for your presentation and you may want to leave some time for questions at the end. You can begin any time.

**Ms Laurie Hall:** I'd like to thank the members of the committee first for staying late today. I'm sure it's been a long day. I was booked in at 5 o'clock last night and couldn't seem to get into the building. You were probably stuck inside here.

**Mr Ed Doyle (Wentworth East):** You just followed the wrong crowd.

**Ms Hall:** Just by way of introduction again, my name is Laurie Hall. I'm the executive director of A-WAY Express. A-WAY is a courier company serving the Metropolitan Toronto area that is run by psychiatric survivors and employs exclusively psychiatric survivors.

I'm speaking today on behalf of the members and employees of A-WAY Express and as a psychiatric survivor myself to express our grave concerns about this Bill 19 that will, among other things, repeal the Advocacy Act. I'd first like to give you an overview of who we are at A-WAY Express, how we came about and why we believe so strongly in the need for advocacy, both personal and systemic.

A-WAY Express is a competitive courier company serving the Metropolitan Toronto area. Our employees are all psychiatric survivors, that is, we have all been involved as consumers in the mental health system in some way and have survived to tell the story: We have all been vulnerable persons and have experienced the system as a vulnerable person.

A-WAY has been in operation for over nine years now, first opening its doors in 1987. We operate with some operating dollars from the Ministry of Health and generate enough income from the courier business of our 800 customer accounts to employ up to 45 couriers at any given time. In total, we employ approximately 55 to 60 people, all of whom are psychiatric survivors and many of whom were written off by the mental health system as permanently unemployed.

There have historically been a complete lack of meaningful employment opportunities available to psychiatric survivors. Traditional employment options for us have been hugely ineffective—programs such as job training programs that graduate a person to no real job opportunities, usually just to another training program; vocational rehabilitation, which was originally based on a model developed to retrain recently physically disabled workers. This has also proven to be of little value to our community. Finally, the most infamous of all, sheltered workshops, otherwise known as putting plastic spoons in bags for 10 cents an hour. When I was in the Whitby Psychiatric Hospital as a teenager, this was professionally referred to as industrial therapy—not much opportunity for advancement.

In the mid-1980s, before A-WAY began, a group of people came together who acknowledge the fact that the mental health system sometimes was leaving people damaged, that people were leaving institutions, sometimes after many years, with no employable skills, no sense of self-worth or dignity, no sense of help for anything more than a rooming house and a disability cheque if they were lucky. There was a need for something that helped people get back their dignity and self-esteem, something that allowed them an opportunity to work and be paid, to get out of the poverty trap they felt doomed to. Nothing existed that could offer that, so they began to develop something new. They began to build A-WAY on the principles that the Advocacy Act also laid out for us: to develop the skills of the community and foster the growth of resources that already existed, to ensure consumer participation and governance, to emphasize education and

training both for each other and society at large. These are the principles on which A-WAY was founded.

The psychiatric survivor community traditionally has had an unemployment rate of 85% to 95%. This rate is unheard of in any other community in Canada and probably the world. The relationship between health and employment has been well-established and is a widely accepted fact, yet with an unemployment rate this high, it is only in the last several years that opportunities for real work for real money have been an option for a small number of psychiatric survivors in Ontario.

As well as the obvious health benefits, the parallel savings in health costs that have been documented are enormous. For employees at A-WAY, employment has meant a decrease in the number of days in hospital; for some, a decreased reliance on medication; for most, a decreased reliance on outpatient psychiatric care and crisis services. The money put in to support these business has translated directly into huge savings to the traditional health care system.

A-WAY is recognized in Ontario, and indeed in many parts of the world, as a leader in our ability to not only create employment opportunities for psychiatric survivors but to run a successful business that is driven and directed by the employees themselves. Currently, A-WAY is only one of several different small businesses across Ontario that are run by and for psychiatric survivors.

More and more people are being released from psychiatric institutions and are being placed back into the community. This government has acknowledged the need to cut institutional spending, to provide the supports in the community and the need to find solutions that work and that are cost-effective. A-WAY is such an example.

From the very beginning, A-WAY was successful because the people who needed employment developed how A-WAY would be set up, how it would run and who would be involved. Non-consumers were involved in the beginning, people with expertise in small business or courier services in particular, who had particular skills to offer yet were committed to the concept of self-help or self-advocacy. A-WAY has developed to the point of being 100% consumer- or survivor-run and operated. This is the key for us and this is the differentiating factor that separates us from other similar models currently being set up by some institutions.

In recent years, successful big businesses have come to realize the benefits of both consumer input and input from front-line employees. This has resulted in improved products, streamlined and improved efficiency in production and an increased commitment to the company due to opportunities for participation by all employees. This concept extends to all areas of society. People, both individuals and communities, know what works best for them. They know better than even the best-intentioned professional what has worked for them in the past and what they need in present circumstances.

Survivor businesses such as A-WAY Express are successful in helping people rebuild their lives because they offer people an opportunity to think for themselves, to learn the skills that they need on the job, taught by their peers. They become involved not only in the day-to-day running of a business but in the long-range planning



and governance of that business. The needs of the community and the development of that community are balanced with the goals of meeting the needs of the customer in a competitive environment. People have an opportunity to find their voice and to use it to help themselves and others in a productive, empowering way. We feel this is the goal of true advocacy.

In December 1992 we saw the highlight of many years of work of many different vulnerable peoples come together in the passing of the Advocacy Act and the commission it was to set up. This commission would have a mandate to provide both individual and systemic advocacy, to take a community development approach, to emphasize education and training, and to ensure consumer participation. For the first time in many, many years of community building and networking, we saw a commission set up that was composed of users of the systems, that was composed of vulnerable people, of people who had experienced the frustration and the difficulties of accessing services that are sometimes outdated, inaccessible, ineffective or inadequate. Many of the same tools that were so successful at A-WAY were to be incorporated into the work of this commission, with some of the same goals.

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We know that people are most healthy when they have some feeling of control over their lives. Psychiatric consumers often emerge from the mental health system damaged and institutionalized, in that they have very little, if any, control over their lives, in some cases not for many, many years. We are told when to get up, when to eat, when and what medications and treatment to take or submit to. Eventually, if we are lucky and if we survive—and some do not—we emerge and are put into the community to live out our lives. We have had our choices taken away for so long, we often can't remember what it is like to make our own decisions. We are so accustomed to having other people make decisions for us that it often takes a long time, with education and training and assistance from people who have been there, to begin to make decisions and advocate on our own behalf.

Becoming employed at A-WAY is the first step for many people in that situation. It works because it was set up and is driven by people who have shared that experience. Similarly, we know the Advocacy Commission would have worked, because the people who know what it is to be a vulnerable person in this society were involved in the process, were involved in the decision-making and were involved in its governance. Most important of all, the commission was committed to ensuring that communities continued to develop and continued to empower each other.

The commission began to develop links across different disability groups, to allow us to begin to discover we had many similar issues and could work together for many of the same goals. It is difficult to work in isolation, with so many people who could benefit and no means or opportunity to get the tools or the message across. We saw the Advocacy Commission as the beginning of the links that were needed.

I have outlined the components of A-WAY that have enabled people to begin to successfully rebuild their lives. These same components are incorporated into other survivor businesses and many grass-roots organizations across the province. They are incorporated because they work, because they are necessary components of a process that allows people to grow and to find their own voice. These same components, we believe, must be the foundation of any proposed legislation directed at true advocacy.

In an ideal world, we would see you tossing out this bill, the Advocacy Act would remain as it is and the Advocacy Commission could be permitted to continue the work it barely had an opportunity to begin. In light of the odds that this will happen, at the very least, I urge you to consider the Advocacy Commission's alternative recommendation, one that was presented to you on Tuesday afternoon: to fund a non-profit, charitable corporation, one that will incorporate these elements, elements that have allowed A-WAY and many other grass-roots disability groups to be successful. Their proposal would see an organization that would foster community development, education and training and systemic advocacy. It would be governed by people with disabilities and would take a cross-disability approach.

We cannot assume that all people have a voice; many do not and many never will. However, many could develop that voice with the proper tools and education and time. Many could learn to advocate on others' behalf, with the proper tools, education and time. Most important of all, we could contribute to changes in the system that helped to cause the damage and silencing in the first place, with the proper tools, education and time. We need this voice to be able to claim back our lives, to begin to recover and to participate once again in society. Too many people have not survived and too many people will never have the opportunity to recover.

This government is proposing to repeal the act that was to provide a means for these things to happen. This government can still provide the opportunity for these things to happen.

We need access to the tools and education that will allow for community development.

We need to be able to develop education and training for each other and for society at large to begin to make the changes that are necessary.

We need the tools and opportunity to address systemic advocacy in a way that will help prevent much of the damage that is being done.

We need a body that will help to develop the links across different disability groups to share information and resources.

To us, a system that incorporates the items just outlined would be the most efficient and cost-effective system. The cost of the alternatives—to do nothing or to allow things to slide along as they have been—has been enormous. To us, it's just a matter of common sense.

**The Vice-Chair:** Thank you very much, Ms Hall. We've got about five minutes per caucus. We're going to start with the Liberal caucus. That would be Ms Caplan.

**Mrs Caplan:** Thank you very much. I appreciate your presentation. Your proposal, however, is that they not

repeal the advocacy legislation. I think that realistically, since that was their campaign platform, they're going to do that. If you wanted to focus on some of the ways the existing legislation could be strengthened, so that not all rights advice and advocacy was lost, I think that might be helpful.

For example, the consent legislation right now really creates a situation where under the Mental Health Act, only in psychiatric facilities are patients guaranteed that they will be told that they have been found incapable and that they do have a right to appeal to the consent board. Would you like to see the legislation also require or expand the mandate—well, first require that all patients be told that they are incapable and that they have a right? That's the first question. Second, the PPAO has been I think very successful over the last almost 20 years now acting as rights advisers and advocates in the psychiatric facilities run by the province. Would you support having their mandate expanded so that they would be the ones who did the training of rights advisers in community hospitals and the community-based organizations, to allow access to rights advisers? Is that a reasonable alternative to nothing?

**Ms Hall:** Yes, I think so. I think they have been very successful in the provincial psychiatric hospitals. I think there is a lot of concern that there will not now be those rights advisers in the general hospitals, where a large population of people suffering mental health problems—that's their main connection. There is still a large population of people, though, even in provincial hospitals, who don't have the knowledge or the awareness or the self-esteem to approach and make an appeal. That's a very terrifying thing.

**Mrs Caplan:** I think this legislation could be improved to ensure that all providers had an obligation to inform individuals that they have been found incapable and that they have a right to appeal. I also think the mandate could be and should be given to the PPAO to both train rights advisers and certify for community hospitals. I think that's something they are the best ones to do; I agree with you.

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Further, I think there is another need that's out there and that the dismantling of the existing Advocacy Commission, which was an opportunity for people to come together and to meet and to discuss these issues—what I would propose and I would like your response to is that you would have advisory committees to the consent board or the consent office, or whatever you want to call it, that could meet: a consumer-patient committee, a family committee and a provider committee. This is the Australian model. They could meet regularly individually, as well as perhaps a couple of times annually together, because often they have different viewpoints. If you had that basis, you'd also have a place where people could call to get advice. Is that a reasonable way? We know they're not going to not repeal the act.

**Ms Hall:** Yes, I think it's reasonable to know, as I mentioned at the end, that there's no chance for it not to be repealed now. I hope they will consider something to replace that.

**Mrs Caplan:** The concern I have is that while the minister has said here that she's prepared to consider new

legislation, the consultation that is taking place clearly states that there will be no new legislation. So we have a conflict there that I'm hoping can be clarified during clause-by-clause. The minister did make a misstatement here at the beginning of these hearings, but groups that are part of that consultation are being told in writing that there's no hope for any legislation, which means this is the only opportunity we're going to have to put something in here that will respond to those clearly identified needs that you've articulated so well.

**The Vice-Chair:** We'll move now to the NDP caucus.

**Mr Marchese:** Thank you, Ms Hall, for your presentation. I guess the frustration I have is that there have been a number of people like yourself who have come to talk about the need for advocacy, support for the Advocacy Commission, support for rights advisers, and it seems like those voices don't appear to be very strong or don't appear to be having much influence on the government, as I can tell. It's sad, because what you have are vulnerable people who, once again, will not be heard or whose voices will be lost, which is what we tried to do through the Advocacy Commission.

It's pretty hard being here—and hard being there—talking about the need for it and why it was created: to give a voice and to give rights to people who otherwise often are excluded, who often may not have a voice or who often lose it for a variety of different reasons. All I can say is I despair.

The Ontario Nursing Home Association came today, and one of the things they support as well is the elimination of the Advocacy Act. So you have a number of people like that who work against individuals like yourself. So I'm not quite sure. You have a government that says, "No, we don't need it," you have other institutions like this saying, "We support the elimination of the Advocacy Act," and then you're on your own with your voice and with a few voices here saying, "We really need to have it," for the protections that one speaks about.

I know Mr Reville came in front of this committee and talked about having a \$3-million proposal for a non-profit corporation that would do community development, training and education, and do some systemic kind of work, which would be the minimum, I think, that they could do. I'm not even sure this government is willing to consider such a proposal that would take care of the concerns you're raising.

I'm not sure what to say other than that we hear you. I'm saddened to be able to say I agree with you, but on the other hand, I think some of your voices are going to be lost, sadly.

**Mrs Boyd:** I think one of the good pieces of news is that your voice is now on the record. You've given a very eloquent description of what advocacy can do. It can never be lost, because it will be on Hansard and it's there. We can always use it to help people to know that there have been groups that have been able to do this. I think if the government does not heed the need for some form of advocacy development mechanism, the communities themselves, led by people like you, will do it.

**Ms Hall:** Thank you very much. It was very important to our community to have this opportunity to make our concerns known today. The survivor community, among



other vulnerable communities, right now is really reeling. I've never seen such despair in the community as I have in the last six months. People are frightened of losing their pensions, they're frightened of losing their housing, they're frightened of losing everything all at once. It's just like the punches come one after another after another. People are really frightened.

There was even some serious discussion about whether or not we should appear at these hearings. Wasn't it better still to continue to hide and not draw attention to ourselves? But we're here anyway and we will continue to survive. I hope this government will see the need to support us.

**The Vice-Chair:** We're going to move to the government side now for five minutes. I guess we'll start with Mr Doyle.

**Mr Doyle:** Thank you very much. I thought your presentation was excellent; I truly was impressed by it. You mentioned at the beginning that you have received some funding from the government?

**Ms Hall:** Yes.

**Mr Doyle:** Do you still receive this funding?

**Ms Hall:** Yes, we do.

**Mr Doyle:** I don't imagine it's a big amount of money.

**Ms Hall:** It's enough to help get us by.

**Mr Doyle:** You mention in your brief, "From the very beginning, A-WAY was successful because the people who needed employment developed how A-WAY would be set up, how it would run and who would be involved." Then you go on to say: "A-WAY has evolved to the point of being 100% consumer- or survivor-run and operated. This is key for us and is the differentiating factor that separates us from other similar models currently being set up by some institutions." So basically, you set yourself up as an organization and have operated that way for approximately nine years.

**Ms Hall:** Yes.

**Mr Doyle:** I would consider you to be a classic advocacy group. Would you agree with that?

**Ms Hall:** Well, it depends on—

**Mr Doyle:** You've advocated on your own behalf, created yourselves and kept yourselves going for nine years.

**Ms Hall:** It's community economic development. A community that had a need came together and developed the solutions to that.

**Mr Doyle:** I would assume that all your people are pretty proud of what you've accomplished.

**Ms Hall:** Yes.

**Mr Doyle:** That's precisely the point that we're trying to make: You did this without an Advocacy Act. You did this on your own. You didn't need legislation of any kind or an act of Parliament to do this. This is basically all that we're saying that we're trying to do.

**Ms Hall:** I think our dismay is that after nine years there are businesses across Ontario that employ approximately 350 people—350 people who have had that opportunity to get their advocacy from each other over nine years. That's such a small, small number, and how

many more—hundreds and hundreds of people—could have come that much further with the gains that we saw with the Advocacy Act? Now to see that being lost again, it's a setback.

**Mr Doyle:** Would you agree that with the assistance of people like yourself this could continue?

**Ms Hall:** I think we need more than that. There's still such a small number of us and there are different needs. A-WAY can address people getting back control of their lives by helping them to earn income and helping them to get self-esteem from working.

**Mr Doyle:** Absolutely.

**Ms Hall:** There are a lot of different disability groups, there are a lot of different issues and A-WAY can address one part of those. What about all the different groups? What about a disability group that's addressing different needs that other psychiatric survivors may have? There's no way to make those links.

The commission was something that would tie all of that together, help us to train and educate other people, help us to pass that information along. I think that's what's needed to really make a difference.

**Mr Doyle:** Thank you very much; I appreciate it.

**Mr Clement:** I do take seriously your last point. There are umbrella organizations, however, in the advocacy world, such as the Ontario Advocacy Coalition, which we heard from very eloquently the other day. I'm hoping that we will be in a position to work with them to achieve some of our mutual goals.

I just wanted the brief time I have left to put on the record, in response to Mrs Caplan, that I don't really see any contradiction with what the minister has said and what we have examined in the focus groups. I think it's pretty clear that unless this committee changes our minds, our initial view at least is that there won't be a new Advocacy Act to replace the old Advocacy Act. However, there may be ways through government legislation—amendments to other acts or other initiatives—that can get us to the goals that we want to get to in a way that is both just and equitable and also cost-efficient. We would very much like to work with you to pursue those and we would love your insight and your input on how best to do that.

I think you've shown some excellent success in the private marketplace. We want to build on those successes. That's what it's all about. I just wanted to say that for the record.

**Mr Guzzo:** Ask him which courier service he uses.

**Mr Clement:** I'll get your card at the end.

**Ms Hall:** Thank you very much. We would very much like to be part of looking at what the options are. I know there are many groups out there that feel they haven't had that opportunity and would look forward to that opportunity.

**The Vice-Chair:** Thank you very much, Ms Hall. I appreciate your presentation, as I know the committee does as well. We will be adjourned now until Monday morning in Thunder Bay at 9 am.

*The committee adjourned at 1759.*





## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

**Chair / Président:** Martiniuk, Gerry (Cambridge PC)

**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

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Chiarelli, Robert (Ottawa West / -Ouest L)

Conway, Sean G. (Renfrew North / -Nord L)

\*Doyle, Ed (Wentworth East / -Est PC)

\*Guzzo, Garry J. (Ottawa-Rideau PC)

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\*Parker, John L. (York East / -Est PC)

\*Ramsay, David (Timiskaming L)

\*Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Orléans) for Mr Conway

Clement, Tony (Brampton South / -Sud) for Mr Klees

Grandmaître, Bernard (Ottawa East / -Est) for Mr Chiarelli

Johns, Helen (Huron) for Mr Hudak

Marchese, Rosario (Fort York) for Mr Hampton

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service

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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Monday 12 February 1996

# Journal des débats (Hansard)

Lundi 12 février 1996

**Standing committee on  
administration of justice**

**Comité permanent de  
l'administration de la justice**

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Monday 12 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Lundi 12 février 1996

*The committee met at 0902 in the Valhalla Inn, Thunder Bay.*

ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

**The Chair (Mr Gerry Martiniuk):** Good morning, ladies and gentlemen. I've lost my clerk, but no doubt she'll be here in a minute. We have certain time constraints today in that we are embarking for Ottawa in the afternoon so we should proceed on schedule.

## ALPHA COURT NON-PROFIT HOUSING CORP

**The Chair:** The first submission is from Alpha Court Non-Profit Housing Corp. Good morning. Could you identify yourself for the purposes of Hansard.

**Ms Deanna Koziy:** I'm Deanna Koziy, the executive director of Alpha Court Non-Profit Housing Corp.

**The Chair:** We have allotted one half-hour to your presentation, including all questions. I will let you know when you're within five minutes of the end by showing my five fingers and we'll proceed from there.

**Ms Koziy:** Hopefully I won't be taking the full 20 minutes.

I'd like to start off by thanking the committee for allowing us to present this morning. Just by way of background, Alpha Court Non-Profit Housing Corp is a community mental health organization which provides case management and supportive housing services to adults who have a serious mental illness. Our goal is to assist these people in achieving the highest level of independence as possible with the least amount of professional intervention. This includes advocating on behalf of the people we serve to ensure equal access to services and prevention against abuse and victimization.

Bill 19 contains many changes and refinements to several complex and important pieces of legislation.

Alpha Court wholeheartedly supports the need to have a balance between the rights of the individual and society's ability to protect an incapable person from personal or economic harm. As so often is the case, it's easy to endorse such a belief. It is often the implementation that makes things difficult. What we'd like to offer today is some of our suggestions regarding the amendments of how we can make this transition a little easier.

As a mental health provider, what we've often found with the existing acts is they were very complex, they were very cumbersome and it was very difficult for a layperson to understand what was involved with them and, more importantly, how it affected the people we are to serve.

We have the responsibility to try to explain these acts to the people we serve and often we found we could not do it, and we often had to bring in lawyers to explain to us how it works so we could explain to our clientele and our family members how it worked. It is my sincere hope that what comes out of these amendments will be something that is very easy for the layperson to understand and, more importantly, for vulnerable people themselves to understand. If you could, at the end of it, put out a quick, easy reference guide in 10 pages or less, I think we'd all be very grateful.

We'd like to start off regarding amendments to the Health Care Consent Act. We'd like to commend the government with regard to the Health Care Consent Act and the Substitute Decisions Act for broadening the definition of who can be included as a substitute decision-maker by clarifying the definition of what exactly is a "parent" to include custodial and access parents and including relatives related by marriage. There are a lot of people out there caring for their family members and the prior definitions exclude a lot of them. So it does allow family members to be more fully involved in making decisions on behalf of their incapable relatives.

We would like to talk a little bit now about the exclusions from the definition of "treatment" as proposed under the health care act. The definition of "treatment" excludes "a treatment that in the circumstances poses little or no risk of harm to the person" with respect to the obligation of the health care practitioner to obtain personal or substitute consent.

The intent of this amendment is obvious. It was to reduce and minimize the existing formalities around delivery of routine low-risk treatments, such as first aid, and to assist, I'm sure, a lot of long-term-care agencies in providing ongoing treatments. However, the proposed amendment does not define what types of treatment fall under the category of "little or no risk of harm," and we're concerned about this creating inconsistencies

regarding obtaining consent, as it is subject to personal interpretation.

There are many different professional groups and bodies listed as health care practitioners and I think they all come from wide-ranging viewpoints and philosophies, so we're concerned that what may be considered low risk to one health care practitioner may not be to another. What we'd like to suggest is the following.

—That the Health Care Consent Act contain clearly articulated guidelines of what types and ranges of treatment would qualify as being low to minimal risk. The regulating and professional bodies of health care practitioners should be asked to assist in the formulation of these guidelines.

—If a person is capable of consent, that consent be sought prior to the administration of low-risk treatments on the understanding that information required about the treatment will be minimal. In reality, many health care practitioners do operate in this manner.

—If a person is incapable of consent with respect to low-risk treatment, the treatment can be administered without the consent of a substitute decision-maker, it falls within the clearly defined definition of low-risk treatment.

—The treatment is in the person's best interests and the health practitioner is not aware of an authorized substitute decision-maker who would object to that treatment.

I'd like to discuss a little bit about the elimination to require formal rights advice to persons determined to be mentally incapable.

Alpha Court does have concern about the elimination of rights advisers and the requirement to provide rights advice to people prior to them being determined mentally incapable. Under the proposed changes, there is no requirement or obligation by health professionals in lieu of a formal rights adviser to inform a person that they have been deemed incapable, nor that they have the right to appeal this finding. We feel that if formal rights advisers are to be eliminated, then the act should require that the health professional who is rendering a decision regarding an individual's mental capacity must inform the individual of the following: the nature of the finding and how it was reached, and the individual's rights to apply to the Consent and Capacity Board for a review of the findings and how to apply to the board.

I'd like to comment on the amendments to the Mental Health Act, specifically regarding the definition of "rights adviser." Bill 19 seeks to amend the definition of "rights adviser" in the Mental Health Act from "in the prescribed circumstance, a person who is a member of a prescribed category, other than a health practitioner or a person who is employed by a health practitioner or health facility" to "a person, or a member of a category of persons, designated by a psychiatric facility or by the minister to perform the functions of a rights adviser under this act in the psychiatric facility."

We're concerned this may create a situation where a serious conflict of interest could exist. If the rights adviser actually is an employee of the psychiatric hospital, the rights adviser then would be responsible for advising people of their rights to contest decisions resulting in their involuntary admittance and treatment by

the hospital which is also the employer of the rights adviser. We're concerned that this places serious liability obligations both on the hospital and on the individuals responsible for providing rights advice, should a person who is rendered for involuntary treatment choose to contest the nature and the quality of the rights advice they received.

Rights advisers have been in place in provincial psychiatric hospitals for the past 10 years and are providing the rights advice required in the proposed amendments. Therefore, we presently have a system in place with trained, qualified rights advisers who are not employees of the hospital and are not in a conflict-of-interest position. We would like to suggest that the present system of providing rights advice to patients in a psychiatric facility remain intact.

#### 0910

Amendments regarding the Substitute Decisions Act:

Powers of attorney: The amendments to this act with respect to powers of attorney are intended to help simplify the witnessing of documents by removing the requirement that the witness have no reason to believe the grantor is incapable of giving power of attorney. The problem with the existing requirement was that the definition was open to interpretation regarding how the witness was to arrive at the belief that the grantor was mentally capable or incapable.

It became cumbersome, as some interpreted the definition to mean that the witness must come to this conclusion using the same criteria that a health professional such as a doctor is required to use when rendering a decision on mental capacity. There was no standard defined as to what constituted reasonable belief for a non-health care professional; in other words, a layperson.

While the proposed amendment resolves this issue, it does, however, open the door for another potential problem. With no requirement on the witness's part to make a judgement regarding a person's mental capacity, a mentally incapable person can sign a power of attorney that may not be in the best interests of that individual. This could result in abuse of powers of attorney, especially when it applies to property matters. The amendments to the act allow a continuing power of attorney for property to override statutory guardianship by the public trustee.

We would like to suggest that the requirement that witnesses must be of the belief that a person is mentally capable remain in the act. However, with the inclusion of what reasonably constitutes forming an opinion regarding mental incapacity—and it's written in some commonsense guidelines that a layperson would know and understand. We're not talking about rigorous physical or mental guidelines that a health care professional would use.

Statutory guardianship of property: The proposed changes with respect to statutory guardianship of property are a positive step forward in allowing families to more easily assume the role of caring for the affairs of their relatives. The proposed amendment will allow a person with a continuing power of attorney with respect to property for that power of attorney to continue once the person is incapable and limiting the role of the public



guardian and trustee is one that we endorse. This endorsement is conditional, however, on our concerns regarding the witnessing requirements of powers of attorney being addressed.

**Activating powers of attorney for personal care:** As a mental health service organization, we would like to support the amendments which allow special provisions to be included in the power of attorney whereby the grantor can waive the right to prevent his or her decision-making powers being removed during incapacity.

This provision is important to people suffering from a serious mental illness. It allows the individual, when well, to put in place a system of care or plan of care that will allow substitute decision-makers to ensure that the individual receives proper mental health care they require when ill.

One of the major problems encountered by family members, care providers and the mentally ill person themselves is often that when the person becomes ill, they refuse treatment. By allowing special provisions in the powers of attorney for personal care, the individual then can have more control over their mental health care and treatment without having to jeopardize everything they worked for when well. This is a serious problem for a lot of mentally ill people who often, when ill, end up losing maybe their jobs, their housing, a lot of things that they worked for, because they were incapable of making competent decisions when ill.

**Repeal of the Advocacy Act:** It is Alpha Court's understanding that the repeal of the Advocacy Act does not represent the government's abandonment of ensuring the interests of vulnerable adults are protected, but rather providing different mechanisms for providing advocacy to vulnerable people.

Historically, family, friends and community-based groups have always advocated for the rights of the most vulnerable in our society, and we will continue to do so. The current economic environment in this province, however, has resulted in service cutbacks to a multitude of social services, including legal aid, thereby creating a situation whereby many of these traditional resources are now less able to advocate for vulnerable people.

This will result in an increasing burden being placed on families and friends who are often taxed to the limit trying to provide the basic necessities for their relative or friend and who often turn to community-based groups to help assist them in advocacy.

When you're advocating on behalf of somebody, to access services is sometimes a very complex issue to go through. There tends to be a lot of bureaucratic red tape, you've got to phone everybody up and down the line to ask: "This person is entitled to these services. How come they're not getting them?" Often what happens is it's very intimidating for family members and it's also very time-consuming. It's important to remember a lot of our family members work and may even have, if it's an elderly parent, their own children; if it's a relative who's mentally ill, they have their own families to contend with. Often they get frustrated and burnt out and they don't know what to do.

Vulnerable people in our society will continue to need advocacy services to ensure the protection of their

interests. What vulnerable people do not need is a highly expensive bureaucratic system which is unwieldy and ineffective. The government does have a responsibility to ensure that the interests of vulnerable people are protected and that an effective, accessible advocacy system is in place in the province of Ontario. If the government is not going to be responsible for the direct provision of advocacy services, it must ensure that the financial resources are available so that this function can be effectively provided in the community.

It is important to recognize that not all vulnerable people have supportive, caring families or are being served by a community agency. There are occasions when it is the family or the agency itself that the vulnerable person may require help in advocating against. Clearly, whatever mechanism replaces the Advocacy Commission must address this issue. Conflicts of interest are bound to arise and vulnerable people need to be assured that a non-partisan body exists to protect them. The need to have some advocates granted with legislated powers to investigate alleged abuses cannot be overlooked as well.

The importance of having properly trained advocates who are qualified cannot be emphasized enough. One of the criticisms of the Advocacy Commission was regarding the lack of training of the advocates and the lack of set standards for conduct. Guidelines, standards, codes of conduct and training programs need to be created to ensure consistency and quality in the provision of advocacy services.

Community groups, families, friends and other stakeholders do want to participate with the government in discussion of how to best provide advocacy services which meet the needs of vulnerable people in our society. It is encouraging to see that the Ministry of Citizenship, Culture and Recreation has already begun holding focus groups to solicit ideas and viewpoints.

In closing, Alpha Court would like to thank the committee for hearing our comments today. As mentioned at the outset of our presentation, Bill 19 is amending some very complex pieces of legislation that were intended to ensure that the rights of the individual were protected and respected, while at the same time providing a vehicle to carry out society's moral obligation to protect and care for the most vulnerable. It is our sincere hope that this committee will be able to utilize the comments by ourselves and others to work towards achieving this goal.

**Mr Ron Johnson (Brantford):** I want to thank you for your presentation. It was certainly insightful. I just want to make a couple of points. You indicated that practitioners could do some rights advice work on their own, and of course no part of the clinical team which we're dealing with will be the rights adviser. The reason for that is conflict of interest, and I want to make that point clear.

You also indicated that your concern was that there was no requirement for a practitioner to inform somebody that they've been found incapable. I want to let you know right off that I have some concerns with that as well. What we've been hearing—we had presentations from the College of Physicians and Surgeons of Ontario and from the College of Nurses and they are clearly saying—and

this has been said by a number of the groups—that informing them and going through that process could result in the deterioration of the health of the individual.

We've heard that from the College of Physicians and Surgeons. They've all said that it's their standard of practice to give that advice when they feel appropriate and to let them know that they've been found incapable. My question to you is, would you feel comfortable if this issue was addressed through regulation within the colleges? Would that make you more comfortable? Does it have to be legislated?

**Ms Koziy:** I'm of two minds, I think. I would like to see people do it because I think people do have a right to be informed that they are being rendered incapable. If you and I were ever in a position where we were having those rights taken away from us, we would like to know it and the reason why. We wouldn't necessarily be happy with it, but we have a right to know it. The reason we're asking for it to be legislated is that I think just common experience is you can ask somebody to do something, but it doesn't necessarily mean they follow through with it.

As a consumer agency and as a family member myself, if I could be assured that the regulatory bodies, the physicians, nurses or any health care practitioner, would advise people of their rights, that they would do this as a matter of fact, then yes, I would feel more comfortable with it. Right now, I'm not feeling terribly confident. I think a lot would but some may not.

**Mr Ron Johnson:** I want to thank you for the answer. I'm going to yield to Mr Clement.

0920

**Mr Tony Clement (Brampton South):** Thank you for your presentation. I will ask one of the two questions I was going to ask. In regard to your commentary on the definition of "treatment" and the problematic wording, in your view, of the "little or no risk of harm" and how that could be interpreted, my concern is, if you put something in legislation—we're dealing with a very fluid situation in terms of treatment practices, which change month to month, let alone year to year, in certain cutting-edge aspects of health care. Would it be satisfactory from your perspective if we dealt with that in the regulations, with having that dialogue with the CPSO among others? Would that be a way to get at the concern you've expressed, or do you have to see it in legislation?

**Ms Koziy:** I think regulations would be sufficient, acknowledging that treatments do change over the course of time. But as long as there's something there that people can refer to, to provide some guidance, because I'm terribly concerned that with that, it's going to open up a whole can of worms from a legal position. I'm not a lawyer, but I can see somebody having a heyday with this if we don't put some guidelines in place.

**The Chair:** I was remiss and I did not identify our local member. Mr Gravelle is with us for the day and I understand Mr Duncan has the great, enjoyable task of being with us for a week.

**Mrs Elinor Caplan (Oriole):** Thank you for an excellent presentation. First, the ministers said that they had an opportunity to consult with groups and organizations. I'm just wondering whether you were part of that consultation.

**Ms Koziy:** Not yet, no.

**Mrs Caplan:** You were not.

Second, I'm going to pick up on Mr Johnson's point, because I think what was pointed out to us by the colleges on this issue of informing people of their incapacity and their right to appeal was the fact that there is so much inconsistency. As I understand it, are you asking for something that would oblige professionals, all professionals no matter which college they are accountable to, to inform of a finding of incapacity, inform people of their right to appeal and let them know how to go about doing that? Was that what you were requesting?

**Ms Koziy:** Yes, that's what I am, especially if somebody has taken the onus, the professional who is responsible declaring somebody incapable, I think they also have a professional obligation to let them know that they have done that.

**Mrs Caplan:** And that could be in the standards of practice or, since there is such inconsistency in approach—what we heard is that that is part of the College of Nurses' standards of practice and if someone didn't do that, they could be disciplined for not living up to the standards of practice. But the College of Physicians and Surgeons said that getting informed consent was, but informing of incapacity was not presently part of their standards of practice and someone would not necessarily be disciplined.

**Ms Koziy:** I think what our concern is, again, the person who's responsible for making the decision, because I think what happens is you get into a team situation with different health care practitioners, and some may have an obligation but if they didn't render the capacity, I think it's easy to shift it around: "I don't have to do it. You have to do it." So I'd like the onus to rest with the person who is making the finding.

**Mrs Caplan:** The last point I want to make, I think it's a very legitimate concern you have about the appointment of rights advisers. What we've heard from the government is that the PPAO will remain intact in the provincially run psych facilities but it could be a hospital administrator in a general hospital with a psych unit who could appoint a rights adviser. What we've been suggesting is that the mandate of the PPAO be expanded to include the psych facilities in general hospitals. Would you support that kind of an approach?

**Ms Koziy:** Yes, we would. I think a lot of provincial psychiatric hospitals are obviously in their communities where there are schedule 1s. We've already got a resource. If you're looking at a cost perspective, maybe looking at how busy they are, can they go over in smaller communities, I imagine, though, in large areas like Metro Toronto and stuff, you'd have to have separate rights advisers.

**Mrs Caplan:** What about in community mental health programs where someone may require treatment, they may be in and out of what would be considered capability but they don't require hospitalization? I think the PPAO, the Psychiatric Patient Advocate Office, could also be the one that could identify people in the communities, that they could ensure the training and the standard and perhaps even certify those who were capable of rights advice from which people could choose. Would you be comfortable with that kind of approach?



**Ms Koziy:** Yes, we would.

**Mrs Marion Boyd (London Centre):** I really enjoyed hearing your presentation. One point you talked about was the issue of the person who is witnessing a power of attorney and this issue of it now being taken out that they have to understand that the person is incapable.

We have many pieces of legislation where we rely on reasonable belief, and it seems to me that I couldn't agree with you more. I think there has to be at least some requirement on the part of that person to assume that the person is not being coerced into signing that power of attorney or indeed does not understand what they are signing. This has been sort of our common law for many, many years in terms of wills and so on. So it seems to me you're right that we need to put some protection in there for people who are in that situation.

Would you say your experience would lead you to be concerned about the way in which people who may or may not be in conflict of interest might make assumptions about their ability to do this when it wasn't appropriate?

**Ms Koziy:** Yes, I am very concerned about that, especially when there are significant financial estates involved. Also, the fact is that a power of attorney may not even be signed by a person's family member. There are a lot of con artists out there who are willing to take advantage of vulnerable people, and I'm very concerned that all of a sudden you may get somebody who is incapable, somebody out there whose sole purpose is to deplete their monetary estate, getting involved and signing this, and the individual's immediate family may not even be aware of it.

**Mrs Boyd:** That cuts both ways, because we certainly have heard the other side of this, that all families are not the loving, helpful people we would like to believe they are, and indeed the families may have a great deal to gain as well. That's the balance that we want to reach. Where families are willing and able and are the most appropriate people to make substitute decisions, that's fine, but where that's not the choice of the person—and I'm sure you have many clients where there may be the case, they have reason not to trust, particularly because we know that familial abuse is often a very common experience for people who have mental illnesses—they may find it a very threatening prospect to have a person who may have been abusive in the past have complete power over them at that point in time.

**Ms Koziy:** Yes.

**Mrs Boyd:** Mr Chair, are we going to be able to have a copy of this presentation? It was an excellent presentation and there were a lot of very good ideas in it.

**The Chair:** It will be copied and distributed once we get back to Queen's Park.

#### THUNDER BAY REGIONAL HOSPITAL

**The Chair:** Thunder Bay Regional Hospital, Ms Homeniuk. Welcome. If others are to take part in the actual submission, I would ask that they also be identified for the purpose of the record.

**Ms Sandi Homeniuk:** Certainly. Thank you for inviting us to make a presentation at these hearings. My name is Sandi Homeniuk. I'm the manager of mental

health services at Thunder Bay Regional Hospital, and with me this morning is Hazel McLean, the manager of psychosocial services, and Sally Hamilton, the quality management coordinator. They will also present with me today.

We welcome the opportunity to participate in these hearings on behalf of Thunder Bay Regional Hospital. As health care practitioners, we must be knowledgeable about the impact of the current legislation and the proposed amendments. At Thunder Bay Regional Hospital we provide a broad range of specialty services to individuals throughout northwestern Ontario. The hospital is a 463-bed acute care general hospital which is also designated as a schedule 1 facility.

The Substitute Decisions Act, the Consent to Treatment Act and the Advocacy Act, although necessary to protect the rights of Ontario's citizens, have proven to be cumbersome for health care providers to interpret and apply. The amendments articulated in Bill 19 clarify and simplify the current legislation. Thunder Bay Regional Hospital supports the amendments in principle, with some recommendations which we will outline.

#### 0930

In this hospital, we have established an interdisciplinary committee which has been meeting for several months to develop practical policies and procedures for implementation of this legislation. Despite numerous educational sessions and availability of guidelines provided by OHA, the College of Physicians and Surgeons and the College of Nurses, policy development has been a very complex task.

One dilemma which arises for health care professionals who treat a variety of patients in a schedule 1 facility, particularly in a general hospital, is whether to regard as psychiatric patients those patients who have "disorders of the mind" such as dementia. These patients are most often being cared for outside of the psychiatric unit; for instance, in a medical or a surgical area. Applying the Mental Health Act is often more manageable than existing legislation. This dilemma may not be clarified as a result of Bill 19, but it is one the general hospital schedule 1 facilities will need to resolve.

For Thunder Bay Regional Hospital, the major issue which arises from Bill 19 with respect to the Mental Health Act is the issue of provision of rights advice to psychiatric patients. A rights adviser means "a person or a member of a category of persons designated by a psychiatric facility or by the minister to perform the functions of a rights adviser under this act in the psychiatric facility."

The Lieutenant Governor in Council will stipulate the designation, qualifications and requirements of these rights advisers, yet it would seem that the rights adviser would or could be an employee of the psychiatric facility. Such an arrangement would be a clear conflict of interest. An employee of the facility should not provide rights advice in respect of a decision rendered by another employee of the same facility.

Moreover, a rights adviser who is an employee of the facility might be perceived as influencing the patient with respect to options, such as application to the Consent and Capacity Review Board. Any influence might be the

result of the adviser's concern for the patient's best interests. A rights adviser not associated with the facility will function according to the directions of the patient and present factual, objective options to him or her, regardless of best interests.

We would like to recommend that the provincial Psychiatric Patient Advocate Office designate an individual to provide rights advice at Thunder Bay Regional Hospital. This office has been established for some time and is very knowledgeable about advocacy issues. Thunder Bay Regional Hospital would also accept other options for the provision of rights advice, provided the individual or category of individual is not an employee of our corporation.

**Ms Hazel McLean:** As Sandi has stated, the amendments do clarify and simplify some sections of the current legislation. There are many aspects of the Advocacy Act, Consent to Treatment Act and Substitute Decisions Act which we do and have supported. For instance, under the current Consent to Treatment Act, patients must be informed when they have been assessed as incapable for a treatment decision and notified of their rights in regard to this assessment.

Our concern is the removal of any reference to rights advisers in the proposed Health Care Consent Act. The system will no longer ensure that patients' rights are respected. We acknowledge that since the enactment of the legislation, rights notification has not been provided consistently. This inconsistency is related to the complexity of developing policies and educating health care practitioners.

We recommend that Bill 19 require health care practitioners to inform patients of a determination of incapacity, with the obvious exception of comatose patients. We also recommend a role for rights advisers in the Health Care Consent Act.

We support the current mandate of the public guardian and trustee to intervene when equal decision-makers are in conflict or if no substitute decision-maker is available. The establishment of a public guardian and trustee office in Thunder Bay has significantly improved our access to these services. We appreciate their prompt attention to referrals and requests.

Bill 19 defines "course of treatment" and provides for a "plan of treatment." We support these changes to the current legislation.

The amendments also significantly improve the process for admission to a long-term care facility when a person is considered incapable of making this decision. We support this section of Bill 19.

The principle of presumed capacity and the guidelines for assessment of capacity will improve the ability of health care practitioners to reliably assess capacity. The challenge for most health care institutions is to provide information to staff at all levels, to ensure they have the knowledge to follow the legislation. We expect that these amendments will facilitate this process.

In summary, Thunder Bay Regional Hospital generally supports Bill 19. We hope that our recommendations with respect to patients' rights will be considered.

Thank you again for allowing Thunder Bay Regional to participate in today's hearings.

**Mrs Caplan:** I appreciate that. I share the concerns that you have. Also, I've said on numerous occasions that there are many parts of the bill which are an improvement over previous legislation, and you've pointed many of those out. The first question I would have is, were you part of any consultation with any of the ministers involved in this legislation prior to the tabling of the act?

**Ms Homeniuk:** No, we weren't.

**Mrs Caplan:** You've raised a couple of issues that I raised with the previous presenter, and I just want to make sure that we clarify that. You said you identified as a major issue the potential conflict of having the hospital administrator appoint a rights adviser, and you go on to suggest that the provincial Psychiatric Patient Advocate Office could have its mandate expanded. You then go to say it could be someone else, and my question is, why duplicate? If you have an office that's working well, which could look after the setting of standards and the training for rights advice and the certification and designation of an individual, why would we want to reinvent the wheel and find some other place to do it?

**Ms Homeniuk:** Absolutely; our first recommendation or first choice would be the provincial Psychiatric Patient Advocate Office. If, for whatever reason, this committee or legislators determine that another group should provide this rights advice, that's fine with us, but we don't believe it should be an individual of Thunder Bay Regional Hospital.

**Mrs Caplan:** I'll just restate again, the concern I have is that when you have something that is working well, if you want to have consistency, especially if you want standards and training to make sure that those people are in the community, are well respected, my own view is that there is absolutely no need to reinvent the wheel and set up another body. It's likely that would bureaucratize it, and then you'd have competing interests, so my support has been for the expansion of the mandate of the PPAO. I think they're quite well respected by those in the field, and I appreciate your comments.

The other point that you make is the inconsistency among the professions. I think there is a view that all have the obligation to seek consent before treatment. The issue comes around the obligation to inform someone of a finding of incapacity, and so I think it's important to separate those two concerns. So the question there is, should the legislation have a statement of principle, for example, that all providers who have the ability to determine incapacity have a obligation to see that the patient is informed of their incapacity and also informed of their right to appeal? Then, in the Regulated Health Professions Act, the individual colleges could determine how they, within their standards of practice, would go about doing it.

The other thing is the act could just say that this should form part of the standards of practice of the profession. How specific do you think this act should be in defining the obligation?

0940

**Ms Homeniuk:** We support that the act should include the provision to inform the individual when there has been a finding of incapacity. One of the problems we encounter with the Regulated Health Professions Act is



the exclusion of social workers. Particularly when it comes to admission to long-term care facilities, social workers are very often involved. So trying to cover, through RHPA, all of those criteria would leave social workers out.

**Mrs Caplan:** That's an excellent point. For those who have been arguing "Leave it to RHPA," social work is not included under RHPA. While no one wants to offend self-governance, you want to make sure that all the providers, whether they are covered by RHPA or not, have that same obligation. I think that's an excellent point.

There's one other point that hasn't been brought up yet and I thought of it while you were speaking, and that is that this act now allows for the appointment of a representative if a patient doesn't object, whereas prior to this, before you could have a representative for the purpose of disclosure of information, you had to have overt consent. I thought of that when you talked about the comatose patient, because of course in this kind of arena there's the black, the comatose patient, and then there are those who are caught in and out of capacity or capability all the time. Then there are those who may not appear competent, because of some communication barrier or whatever, but in fact are.

You also raised the issue of the difference between a clear mental disorder under the Mental Health Act and those with a physical injury, such as brain injury and so forth. That's why I was also thinking about the fact that people now, if they're silent on the appointment of a representative and the differences of those kinds of patients under the different acts—I thought you might want to just comment a bit about the different kinds of patients you're dealing with and also the fact that right now you have to get their consent before a representative, no matter which act they're under.

**Ms Homeniuk:** It's been our experience in psychiatry that although every patient on admission is given the option to appoint a personal representative should he later become incapable, I believe maybe one individual in the past two years has chosen to follow that option. I think it should still be an option for people; it's just not utilized very often.

**Mrs Caplan:** You ask them?

**Ms Homeniuk:** Every single patient.

**Mrs Caplan:** What would happen if they say no, they don't want to appoint anybody on admission? When they become incapable, then the procedure is—

**Ms Homeniuk:** We follow the act as it's set out.

**Mrs Caplan:** Do you see any reason for the change in this legislation? Everyone I've spoken to has said that process has worked just fine.

**Ms Homeniuk:** The process has worked fine. In a general hospital schedule 1 psychiatric facility, we may or may not have the volume of treatment-incapable psychiatric patients that, say, a tertiary provincial psychiatric facility might have. We've not done any comparison in statistics, but just offhand I would say we probably have fewer treatment-incapable individuals than tertiary care.

**Mrs Boyd:** Thank you very much for your presentation. One of the things that makes it really interesting for

us is hearing from you because of the breadth of experience you have, having acute-care as well as psychiatric facilities in the same hospital. It interests me that when you talked about the rights advice, you were talking about the psychiatric part of that, but really, it's true in the other series of situations as well, isn't it? You would see a lot of people in the geriatric area, you would see a lot of people who were accident victims, you would see a lot of people who might have diseases such as MS or AIDS. All of those might be in and out of capacity for various reasons at different times, so it's quite a lot of experience you have of the full range of situations.

I certainly agree with you that, as regards the Mental Health Act, the psychiatric patient advisers have really been wonderful. I remember working with them at the beginning, with great resistance on the part of most of the professionals in the health field to the psychiatric advisers initially because it was assumed they would be interfering with the prerogatives of those particular professionals. I think they have become part of the team in a way that's most appropriate. They're not part of the team in that they're employees of the same facility, but they're seen as being helpful rather than obstructive. I would agree with you that it really has worked very well.

We've heard from physicians particularly on this issue of harming people by telling them about incapacity, and Mr Johnson raised this. One of the things that really concerns me is that professional assumption that somehow the physician knows better than the patient. It worries me. I think it's out of a caring aspect—I'm not suggesting there's any other motivation—but I think we know now, with the experience we've had in geriatrics, for example, that we made assumptions about what people were capable of doing and deciding that have proven to be absolutely wrong, and I think the rights advisers in the mental health field have shown the same thing, that once you're clear with people, they very often are quite prepared to make sensible decisions. Could you comment on that?

**Ms McLean:** Actually, I'd really like to comment. It's something that health care practitioners in the acute-care field are not necessarily comfortable with yet. I don't think it's really been our practice to inform people that we don't think they're capable so we're going to a substitute decision-maker. The previous legislation, in terms of the way we had to do it—to read a form that was very long and wordy—was not a humane way of doing it, and I can understand the physicians objecting to that. But if they're allowed some latitude in judgement about how to communicate with this patient, "I really think I'm going to have to go to your wife or to your son to make this decision in a humane way," I think that's reasonable. We need to teach health care practitioners that it's our responsibility that we should do that.

There still has to be the rights adviser who comes in and explains about the review board, that aspect. That should not be the responsibility of the health care practitioner. The health care practitioner should in some way inform the patient, "We don't consider you capable of making this decision." I don't know whether Sally would like to add to that from a risk management point of view,



because we've had a couple of situations with surgeons where Sally's worked through this with them.

**Ms Sally Hamilton:** My experience is that we had to coach the health care professionals through the process, because it really is quite a complex one and something they've had to learn as we've gone along. Once they've been coached through it, I don't think they find it as onerous as they thought it would be. Our experience has also been that the patients have appreciated having that opportunity to know more about what is going on with their care. I think it's been a very positive experience, in fact. I appreciate the fact that it needs to get less complex, and I think the legislation helps to do that, but I like the fact that our patients have that opportunity to respond to being told they are incapable. Overall, for hospitals in general and for patients, it is a much better situation.

**Mrs Boyd:** It's often a relief, isn't it, for a patient? They may have been feeling confused and feeling the huge burden of this, particularly in the geriatric area. Often, having somebody say, "Do you really feel you're able to make this decision? How about some help?" would be very helpful to a lot of them.

**Ms Hamilton:** Our experience with that—and again, it's limited—is that there may be some disbelief on the part of the patient. That leads them to request the rights adviser to come in and they work their way through that and feel very comfortable with the decisions being made, whereas in retrospect, if that had not happened, there's a good possibility that they would feel they had not been given an opportunity to respond to being found incapable.

**Mr Rosario Marchese (Fort York):** It's interesting how various people in the field treat these concerns differently. We had—I believe she may have been a nurse, but I don't remember. She read out the form, and the way she read it, all of us were offended.

It's interesting that what you're suggesting is that rights notification is important, but how you handle that is the way to deal with rights advice. You can either decide, "This is so complicated and cumbersome that we don't want to do it," or "Rights advice is important, but this is cumbersome and perhaps we can make it a little more flexible." I appreciate that you take rights advice seriously. What you didn't say—and I want to hear it—is why you think informing the individual is so important.

**Ms Homeniuk:** One of the reasons we feel quite strongly about the provision of rights advice is that it speaks to our corporation's values to respect the patient and to treat the patient in a manner that promotes his dignity. We believe providing rights will support those values.

**Mrs Boyd:** One of the issues that has arisen with respect to the plan of treatment and to what is treatment and what is non-treatment—several different speakers have talked about it—is where nutrition and hydration fits into that picture, whether that's treatment or non-treatment, and the issue of consent to non-nutrition, non-hydration. Could you comment on that.

**Ms Homeniuk:** I can comment on that with respect to mental health because it does crop up periodically that individuals with mental illness will need to be nourished and hydrated when they would perhaps choose otherwise.

We've not had a problem in doing those kinds of things under the existing Mental Health Act, in describing that as a plan of treatment. I guess it's not been challenged.

**Mr Frank Klees (York-Mackenzie):** Thank you for your presentation. I would like to follow up on the conflict-of-interest issue you raised. It's certainly a recurring theme, and we want to make sure we get this right. Your specific concern is the possibility of having an employee of a facility appointed as a rights adviser, that this would create a conflict situation. Given that the regulation under Bill 19 regarding rights advisers would not restrict a hospital from making arrangements with a third party to provide that rights advice, would that flexibility by regulation give you a level of comfort? Would that address your concern?

**Ms Homeniuk:** Partially. There would still be a perception that the third party had a direct-line authority to the corporation and in some way the corporation might still be pulling the strings with respect to rights advice. It's further removed than having a front-line employee providing that advice, but I think it would be better to have an independent office.

**Mr Klees:** I'm interested in that. You have some broad experience in this. Do you have specific experiences in your own practice within your facility that give you reason to believe that if a third party were appointed by the hospital itself, there would be a conflict situation? Are you speaking from experience on this? We have to get to the root of this, why we feel this issue of trust isn't there.

**Ms Homeniuk:** I can't say from direct experience that I've been aware of other potential conflict-of-interest situations due to a third-party or purchased-service arrangement for rights advice or for any other kind of service. Whether or not the system is fair, there needs to be a perception of fairness. To create a perception of fairness, you have to remove the office that provides rights advice from the facility making the decisions whereby the individual is rendered incapable.

**Mr Klees:** The PPAO would in fact be used to train rights advisers. Right now the PPAO, I believe, serves 10 psychiatric facilities in the province, and one of the problems is ready access. We're trying to streamline this process and make sure that rights advice is available when it is needed. To broaden the scope in terms of who can provide that rights advice is really an integral part of bringing that efficiency to the system. Given the fact that we would use the PPAO as the trainers for individuals who would provide that rights advice, does that give you a sense of comfort? Do you feel we could work with that to ensure that we have qualified people in the field to provide that rights advice?

**Mr Homeniuk:** I think that would alleviate the concern about a trained individual providing rights advice. It doesn't answer the question of who that individual would be, whether that individual would be an employee of the hospital or an employee of an external agency contracted to provide a service.

**Mr Klees:** It's been my experience in the short time I've served as a member of the Legislature that employees of psychiatric facilities as well as schedule 1 hospitals have come to me advocating on behalf of patients within



the facilities they serve. I have no doubt that the nurses and the professional people serving in these facilities care deeply about the people they are serving. To get back to the core issue—I don't want to debate this, because we want to get it right, as I said before, but given what I've seen from professionals in the field, who care deeply about their patients, why don't we believe we could trust employees of a facility to provide this advice?

**Ms Homeniuk:** Your comment is one I can use and build upon to explain why I think that person shouldn't be an employee. I'll use the example of an individual who's quite mentally ill and perhaps is paranoid or delusional and doesn't want to take his medication. As a health care practitioner, I believe that individual should take it, that he is suffering unnecessarily and that if he were to take medication it would alleviate the symptoms he is experiencing and his suffering. In the best interests of the patient I might believe he should take that medication. I may not maybe emphasize strongly enough, or might soft-pedal, his option to apply to the review board or his right to continue to refuse to take that medication. As a health care practitioner, I'm involved with this individual on a different level and I want what's best for him. I might not even tell him of the option to apply to the review board. I know what that does to an organization. It's time-consuming; it takes people away from their practices to prepare for a board hearing, which can be lengthy. There's also an avenue to appeal a review board decision. As a health care practitioner, in the best interests of the patient, it might be best if he just takes that medication. So if it were entrusted to me to provide that rights advice, I couldn't say I would be as objective, fair and unbiased towards that patient, and he needs to have his rights explained in a fair, objective and unbiased manner.

**Mr John L. Parker (York East):** The question was raised earlier of whether you had been consulted in the process of establishing this new bill. Did you attempt to contact the Attorney General's office or the Health ministry in any respect in the preparation of the bill?

**Ms Homeniuk:** No, I didn't.

**Mr Parker:** I just wanted to make the point that about 80,000 people did by telephone and 30,000 did by letter, which makes it a bit difficult for us to get back to all those people who volunteered input and even more difficult to follow up with others who we hadn't heard from, but there is this process of consulting. We think we've recognize the message that was coming to the government. We tried to address the message we received loud and clear in the bill we have prepared. We're fine-tuning some of the details now and we're very grateful to you for your help in that process.

On the subject of disclosure to someone who has been found incompetent that that finding has been made, we're grappling with that. We're receiving different advice from different quarters on whether that should be done or shouldn't be done, and if it's to be done, just how it should be done. Could you give us your guidance on how you would like to see this bill amended to address that point?

**Ms McLean:** As I said earlier, it needs to be amended to allow the health care practitioner to develop a humane

way of doing it. They need to know it is their responsibility to inform the patient that they do not feel that patient is capable of consenting to the treatment that's being proposed and that they will be going to see a substitute decision-maker. Likely there should also be something in writing left for the patient, but something that's more user-friendly, that's written in lay terms so they can understand the language, and that they still have the right to request a rights adviser or not.

**1000**

**The Chair:** May I thank you for taking the trouble to come today. We really appreciate the practical application of the philosophy we're discussing here. It's been most valuable input. Thank you.

**Mrs Caplan:** I have a question while we're waiting for the next delegation. Mr Klees, could you just point out to me what section of the act gives the PPAO a mandate for training rights advisers; I can't find it.

*Interjection.*

**Mrs Caplan:** I think people would have more comfort if the mandate was in the act. If you want to bring in an amendment, I'd support that.

#### PERSONS UNITED FOR SELF-HELP, NORTHWEST

**The Chair:** We have the Persons United for Self-Help in northwest Ontario; Mr Rick Elms, president. Good morning. Could you identify everyone who will be taking part; this is for the purpose of Hansard.

**Ms Marilyn Warf:** Rick Elms is president of PUSH Northwest, Janet Turner is a community development worker with PUSH Northwest and Floyd Balias is a member. I'm Marilyn Warf, regional director.

Thank you very much for the opportunity to address this group regarding Bill 19. Just for background information, PUSH, Northwest is an organization of people with disabilities. It is of great concern to individuals with disabilities because they are the ones deemed vulnerable in this bill. This is the voice of those consumers. Our presentation doesn't refer to specific sections or subsections, it won't be technical, it will be our opinions of what the impact is for people with disabilities regarding the information that is in Bill 19. These are the people who are deemed vulnerable, and included in that as well are seniors, who become vulnerable due to circumstances relating to aging.

Beyond our first impressions is the fact that we don't believe this bill is what's quoted, that the act creates a presumption of capacity for all persons. We believe Bill 19 will make it easier to obtain an incapacity assessment. We believe this bill makes more people vulnerable under conditions for substitute decision-makers and makes it harder to reverse a decision. Rather than capacity review, the bill refers to an appeal to reverse an assessment, so we're looking at a lot of general comments regarding the bill and some specifics regarding incapacity.

You will hear from individuals with psychiatric disabilities with their consumer organization that's presenting later in the day.

It was the opinion of some people that the previous Advocacy Act, although it did address some of the same things we're talking about with the companion legislation, in some small ways gave too much absolute power to the



person with the disability themselves. There was some concern about that and there were some groups that spoke to the government about that. I think that was considered prior to the drafting of Bill 19, but it's our opinion that it's gone too far the other way—that there is no balance, it's lost its balance, it's too far in the hands of caregivers and substitute decision-makers without the individuals themselves. That was certainly addressed in the previous presentation, where they were saying, don't assume that a person with a disability doesn't have the capacity to make those decisions when they have the respect given them to accommodate whatever their disability is and the time to think about and be given the information regarding their own choices in relation to their own care, their own property, or whatever it is.

We do need an Advocacy Act of some form with consent and substitute-decision-making components in it, but we need independent community-based rights advisers and advocates to go with it. So information provided in this presentation, and many more that I'm certain you'll hear across with your consultations—it's really a very big fear and a very real fear that those who are vulnerable will be more so under this bill.

Three key areas concern us. The legislation eliminates independent advocates and rights advisers who could provide information about rights to vulnerable people and assist them in asserting those rights. There is an assumption that the family and paid caregiver will always act in the best interests of vulnerable people, justifying the removal of the accountability mechanisms. There is also a concern that the legislation makes it easier for someone to gain control over all of a vulnerable person's decision-making rather than working with the vulnerable person to allow them the greatest degree of autonomy possible.

Bill 19 will have significant impact on the lives of vulnerable persons like those with disabilities and seniors. Bill 19 will have an enormous impact on the lives of vulnerable people. It will eliminate fundamental rights and protection intended to ensure that people could retain as much autonomy as possible in their lives.

The government describes Bill 19 as a way of getting the government out of the lives of citizens and returning decision-making to the families when in fact the changes will mean that vulnerable people will have the government more able to have a controlling role in their life. They've lost some of those rights to have their own voice heard in relation to decision-making. Of paramount concern is the definite possibility of an increased risk of abuse by vulnerable people.

Bill 19 removes reference to advocates and rights advisers who, under the old Advocacy Act and the companion legislation, provided those rights. There will no longer be advocates and rights advisers to help vulnerable people understand their rights and express their wishes. Gone are plans to develop systemic advocates to promote the rights of vulnerable people and identify and try to remedy situations which put vulnerable people at risk.

Under Bill 19 the only situation where rights advisers will be permitted is in psychiatric facilities. It talks directly about psychiatric facilities, and we really weren't sure, because of the wording of the bill, whether that also

means in the psychiatric wards in the general hospitals. Do they not have the same rights? Does it have to be within a psychiatric facility? I don't know whether you realize—I'm sure some of you do—that we are in that whole situation right now where we're looking at mental health care and planning for that. What does Bill 19 mean about rights advice, even in facilities, when they change?

The other concern of ours is, does this mean that the government assumes that the only time people are vulnerable or need rights advice is when they're institutionalized? What about situations that arise in day-to-day living? Where are the rights advisers for the general public? Rights advisers help families too. It's not just the individuals rights advisers help; it's families that are involved in situations that happen when you get into an incapacity assessment or capacity assessment. So don't just think of it in terms of an individual; it's a broader thing than that.

Without community-based advocates who take responsibility for those who are vulnerable in the community, where do they go? Who looks after those individuals? In northwestern Ontario, we have a lot of individuals who come into this area—examples are to cut timber or to work in the lake systems—and they end up staying here. They don't always have the support mechanisms of family. This bill assumes that everybody has support mechanisms that always will look after them and look after their best interests. That's not true.

We had a situation just recently where we had very vulnerable men, older men who were those kind of people who were without family supports. They weren't living in adequate living conditions. They were not healthy because of being improperly fed. Nobody was looking after them. They were vulnerable, very vulnerable. Nobody was there to help them and they actually died in a rooming house fire. Where is Bill 19 covering that extent? Those people are not institutionalized. Without community-based advocates, where is the assistance for those people who are vulnerable, not necessarily through disability or aging but in those other situations as well?

#### 1010

Under capacity assessments, the capacity assessors will only be required to inform a person being assessed regarding the purpose of the assessment and the consequences of a finding of incapacity. Capacity assessors under Bill 19 are not obligated to inform the person being assessed of their right to refuse the assessment. There's no obligation under Bill 19 to inform the person of their rights to challenge the finding of incapacity, either at the Consent and Capacity Board or in court, depending on the circumstances under which the assessment was done.

Where's the right of the individual for information regarding a procedure that can have profound repercussions? If we're setting this person up in a situation where whatever the finding is will greatly impact their life, where are the advocates and where are the rights advisers outside of those institutional care settings?

Bill 19 must include a directive for informing individuals of their rights to refuse a capacity assessment. So although you have instructions, you don't have the



guidelines, you don't have the accountability built into this bill.

Under the statutory guardianship division, on the finding of incapacity the vulnerable person under Bill 19 no longer has an opportunity to prevent statutory guardianship by objecting. This means that the public guardian and trustee becomes the statutory guardian of a person with complete control over all of their property as soon as they receive a capacity assessment that the person is incapable. Bill 19 removes the requirement that the vulnerable person have an opportunity to meet with the rights adviser before the public guardian and trustee becomes their guardian to ensure that they understand the implications of statutory guardianship and their rights.

Instead, Bill 19 simply requires that the PGT inform the person "in a manner that the public guardian and trustee considers appropriate" that the PGT has become statutory guardian and that they may apply to the Consent and Capacity Board for a review of the assessor's finding that they are incapable. The incapable person cannot terminate a statutory guardianship without a court order or another capacity assessment. With the elimination of advocates and rights advisers, how will a vulnerable person know that under Bill 19 they are required to object to a guardianship order?

Under Bill 19 there is potential for serious invasion of privacy for the vulnerable person by specifying persons to whom personal information about vulnerable persons may be disclosed without their consent and possibly without their knowledge. Those are two key components. The bill is not tight enough in requiring anybody to make sure that you know that I'm going to go and check out what your private information is without your knowledge and without your consent. Those are two key components that, if you're going to write any kind of legislation to protect vulnerable people, have to be there.

Under Bill 19 guardians will now be free to use restraints and monitoring devices without any accountability or even provide information pertaining to the intended use of restraints.

Under Bill 19 a person who is paid to provide health care or residential social or support services to an incapable person can be appointed as the guardian of the property of the vulnerable person. This sets up a very definite conflict of interest situation with a person who has the power to make decisions about how to spend a person's money, where they live etc when that decision-maker will be the direct beneficiary of those decisions that are made.

Bill 19 is assuming that all paid caregivers are acting in the best interests of the individuals. What if the individual is non-verbal and living in a support service living unit and a paid caregiver is the communicator for that individual, but the paid caregiver is also the abuser? Who speaks for the vulnerable individual? So you've got a person who's non-verbal living in an SSLU with a paid caregiver who is the abuser. Where is the help? You don't have anything that supports that individual. That person is vulnerable to start with due to disability and you haven't protected that vulnerable person under Bill 19. There is nothing in that legislation that provides

anything that would guarantee that person has a place to go for their own protection.

Bill 19 gives paid caregivers priority over the public guardian and trustee as the court-appointed guardian. This allows for the creation of a high-risk situation for vulnerable persons, particularly in light of the elimination of rights advisers and advocates, who may be able to identify abusive caregivers. The elimination of accountability for financial reports and the use of restraints makes the situation even more of a dangerous one for those who are vulnerable. So it's easy to get control, it's easy to get access of money, it's easy to make decisions and it's really dangerous. You've put vulnerable people at a higher risk because you haven't covered all the holes in the legislation.

If the paid caregiver has rights for decision-making and care and property, who's going to intervene when the paid caregiver decides to spend the individual's money, not on more services but on a fancier apartment or trips or dining out? You've given that person total autonomy over the care and the decision-making for spending that money. If you think it's unrealistic to think that those situations happen, it's not. It's more prevalent than you would like to believe it is; it's not a realistic expectation to think that everybody who is in that position is going to do it appropriately, with the best interests of those individuals coming first. The fact is that this situation is a very real concern for persons with disabilities. I think that as the understanding of this bill increases, you will find far more feedback from seniors when they realize that their vulnerability is increased under this bill too.

Powers of attorney for property and personal care. The changes to this section dealing with the powers of attorney for personal care and property now allow an individual to specify what criteria are to be used to determine when the power of attorney comes into effect, and if they choose, who should assess their capacity. Of concern under Bill 19 is the elimination of any requirement or obligation on the person who has the power of attorney to explain to vulnerable individuals personal care options and decisions and inform them that they have the right to object to any decision.

We're not playing fair here. Unless it's legislated, you don't have the clout. The legislation doesn't specify what the requirements are to inform, and make sure that people know it's not going to happen unless it's legislated. We'd like to believe that people are always going to do good things, but again, if you're going to build it to cover people who are vulnerable, write something into the legislation that makes it mandatory. With those kinds of requirements, it means that vulnerable people may easily be excluded from the decision-making regarding their own care and may be treated against their will. It also takes away the autonomy of the vulnerable person and may lead to abuse by the person with the decision-making power.

Powers of attorney for personal care with special powers. Under previous legislation, there were controls and systems in place to attempt to ensure that the use of force and confinement with this type of power of attorney was not abused. There was also provision for the vulnerable person to challenge a capacity assessment. Bill 19

removes all procedural protection for the vulnerable person, not just for future powers of attorney but for those that have already been validated. Bill 19 removes the requirement that a capacity assessment be completed prior to the power of attorney coming into effect. People who thought they were protecting their vulnerability by preparing powers of attorney are in fact very vulnerable due to the gross lack of accountability. For those becoming decision-makers under Bill 19, as a final step in increasing the vulnerability of individuals, the person granting the power of attorney must waive his or her right to challenge a finding of incapacity at the Consent and Capacity Review Board. The provisions under Bill 19 basically eliminate the right of the grantor to be presumed capable and increase the possibility that the power of attorney will be abused.

There is great need to provide public information as to the status of the power-of-attorney kits which were widely used under the previous government. People need to know if their written wishes are still valid in light of the repeal of the Advocacy Act, Consent to Treatment Act and Substitute Decisions Act. People also need to know the reality that their potential vulnerability is increased under Bill 19. What we're talking about there is that there was wide distribution and use of the power of attorney kits that came with the other legislation. Is that in place under Bill 19? Is it safe? Does it have to be rewritten? Should we redistribute? Should they be somehow filed in a different manner? We're not sure, that's not clear and there's not a lot of public information regarding that.

Breach of privacy, public records. The government will be allowed to create public records of information relating to the guardians of property and the person, as well as the attorney for personal care and property. It's a total invasion of privacy to allow this type of information to become public record. I think you have more protection under criminal activities than you do under this component of Bill 19. If there is a need to disclose the fact that there's a substitute decision-maker for a person, then it should be done so only when there's a compelling need to disclose the information, and under strict legislated criteria for the release of such information. Unless you tighten it up, it's open for abuse and it will not be respected; and if you don't respect it, the person is not respected.

1020

To give you a bit of background, for people with disabilities—I don't see anybody with a disability on your panel. You're talking a great deal about legislation that impacts directly on their lives. I'm accompanied by three people whom you're talking about who are very vulnerable to other people making decisions on their behalf. I would certainly hope that at some point the government consults with the people who have their lives impacted by this kind of legislation.

Bill 19 permits health care providers regarding the Regulated Health Professions Act or any person providing health care or residential social training or support services to disclose personal information, including medical information, about a vulnerable person. Information may be given to a capacity assessor, to persons who

have made or stated in writing that they intend to make an application to appoint a guardian of property or for personal care, or to the public guardian and trustee.

Why is your right to privacy violated when you're deemed to have become vulnerable? When you're most vulnerable, you're more vulnerable because you've lost your right for privacy. Do you lose fundamental rights at a time when you need them the most? There's nothing to ensure that a person is knowledgeable about the violation of their privacy or any opportunity for them to challenge this violation. This has great potential for the abuse of power, and there's no justification for access to this kind of information prior to any court hearing. In that case, you can see having to provide that information, but until such point as there is a real need for that kind of information being released, people have the right to that privacy, and it's not protected the way Bill 19 is written.

Under the expanded definition of "family," the scope of the Health Care Consent Act goes beyond that of the Consent to Treatment Act and encompasses the admission of a person to a facility even when no treatment is necessary. This act also allows for consent in areas of personal assistance plans and activities of daily living. The power for decision-making under this act is given to a person holding power of attorney, a spouse or partner, a child or parent, followed by other members of the family. The problem with this section is the broadened definition of "family" to include anyone related by blood, marriage or adoption. There's no definition of how close the relationship needs to be. For example, it's not clear whether the brother of a sibling's spouse would be a relative under this definition. So if you're going to define a person who is designated as a decision-maker, let's make sure that's tight enough so that it doesn't become someone who doesn't know anything about an individual who's very far removed.

Under Bill 19, there's no provision for the relationship of those who fit the definition of "family." Under previous legislation, there was a requirement that persons acting as substitute decision-makers make a statement that they had been in contact with the person within the last 12 months and believed that the person would want them to be their decision-maker. There's no such provision under Bill 19. Even the word "contact" left much to be desired in the previous legislation, but under Bill 19 there's no requirement at all for the type of relationship the family members have, only that they fit the definition of "family." This is a critical condition of who has the right to make decisions for an individual, particularly in light of the reduced accountability and increased power given to the family under Bill 19.

How, under Bill 19, can individuals be sure that their wishes that were declared when they were capable are being followed once they are vulnerable? During preliminary discussion regarding the implications of the bill, a young woman involved in a meeting was absolutely appalled by that section of the legislation. This is a young woman who is very competent, who works in public radio. We were talking about doing public information sessions regarding Bill 19, and she went: "Oh, my God, that's me. I am very vulnerable under Bill 19. I'm totally healthy right now; I'm very capable, but should I become



incapable through accident or disability—I haven't seen my family for 10 years. My friends know what I want; my friends know my wishes." Under this legislation her family, and it could be anybody who fits that description of "family," could come in and make decisions they thought were appropriate and they don't even know this young woman any more, but her friends would not be allowed to do that under the way this bill is written.

There's a concern for us in discrimination against persons with a disability. Under Bill 19, health care practitioners are allowed to treat capable people without consent if they cannot communicate because of disability or language. If you haven't noticed, Janet's deafened. She's reading my lips. It's an oral translation, and she's extremely good at lip-reading and you would forget that she's deafened. But in a situation where she's been in an accident, she is not going to be calm enough to be able to read lips; if someone has a mustache, it's all over. Or say they have a speech difficulty themselves: Janet's non-communicative.

Does that mean that she, as a very capable, intelligent person, loses her ability to make her own decisions because a health care practitioner no longer has to accommodate? What about those who are culturally deaf and do not lip-read? Are you going to call an ASL interpreter in or are you just going to assume that this person no longer has the right to make her own decisions because she can't communicate? How are you going to cover those bases? It has not been addressed. You're not addressing people with disabilities under this legislation. Those are real people, very intelligent people who have the right to make their own decisions and they have not been addressed in this bill at all. There's no provision at all for accommodating the disability, and it's a violation. Because the practitioner is covered under the common law for any liability relating to decision-making, challenging a decision made for individuals in that situation would be extremely difficult.

The HCCA does not make any requirement that persons found to be incapable be told that they are being treated as persons who are deemed incapable or that they have the right to challenge the assessment or that they may apply to the Consent and Capacity Review Board to have someone other than the one who is acting in the role of decision-maker replaced by another person. Who is going to be out there to tell her that she doesn't have to put up with whoever is making the decisions? Again non-verbal; it's supposed to be an indication of not wanting the treatment that is being offered, but where is the person to advise that individual that she doesn't have to do that, and where is the individual to come in and be the rights adviser or the advocate?

How is the young woman in the previous scenario to know that she does not need to have an absentee family member reappear to make decisions on her behalf? Where are the rights advisers? How can this legislation pretend to be protection for those who have become vulnerable? We haven't made any provisions in this at all. If you're going to have a bill that covers this kind of stuff, you have to do some community awareness. We know about it because we're dealing with people who are deemed vulnerable. What about the general public? What infor-

mation have you got out there to tell the general public what their vulnerability is under this bill as well? They're not going to address it until they're in the situation, and with no advocates and rights advisers, who's going to step in and tell them? They've never known about this before, nor are they going to have anybody to address that with them.

Many people in the government have said that the outcry against the provisions of Bill 19 is only the response of special-interest groups. Persons with a disability and seniors are not special-interest groups. They are the fibre of our society. So when you're looking at this legislation, don't think that it only applies to a very small segment of the population. This bill has far-reaching implications not only for those who are vulnerable now, but for anyone.

Just to give you a bit of a scenario: If, say, you and your wife are in a car accident and your wife dies and you sustain head injuries so that you are non-verbal, and it is determined that you are incapable of making your own decisions, you are now vulnerable under this bill. The same scenario can be repeated in cases of stroke or other injury. In a case where you are declared incapable and you are vulnerable, you'd better hope that your family members will make the decisions on your behalf that are aligned with your wishes.

What if the decision-making was, under the definition of "family," given to an estranged child or another family member? Would your wellbeing be the priority? Or when there are estates involved, does money become the motivator rather than the priority for health care? We'd like to think that isn't out there, but that's not the real world. In a perfect world that would be the issue, but we don't live in a perfect world and the lack of accountability in Bill 19 allows too much room for the abuse of power.

1030

A scenario that would be possible under Bill 19 is that a son declares he's intending to have himself appointed as the guardian for his aging mother. She's aging and has taken mood-altering drugs during the sickness and death of her husband. The son has access to personal information. The scene is set for the son to declare himself as his mother's decision-maker for property and care. The mother is moved out of her luxury apartment to a one-bedroom apartment. The mother is told she spends too much money on her annual trip to Florida and the son refuses to give her the money. Who is going to advise the mother that she has to take her son to court to overturn him being appointed as her decision-maker and guardian? That's our impression of the degree of vulnerability even for the general public under this bill.

We believe that Bill 19 was written with a bit of a Pollyanna attitude that everyone who is a family member or caregiver is always acting in the best interests of the individual. Reality tells us differently. Statistics show that 40% to 45% of abuse is caused by a family member and that another 40% to 45% is caused by caregivers. Those are shocking statistics, but what is even more shocking is that Bill 19 was written supposedly to protect vulnerable people when in fact it has removed the independent



advocates and rights advisers and rendered vulnerable people even more vulnerable.

How can Bill 19 eliminate the role of trained advocates and allow medical staff to be advocates? Would the rights and the best treatments be awarded to individuals or would the issues relating to the medical facility and biases enter into the decision-making, and who would make that decision-maker accountable? We heard that in the previous presentation. That is a very real concern. That's coming from those health care practitioners in those facilities and they know the possibility is there.

If Bill 19 was intended to protect vulnerable individuals, it certainly missed the mark. If the intent was to allow situations where vulnerable people are more at risk for abuse by family and caregivers, it's hit the mark.

We would like more consultations with people with disabilities. That's not being done. We would like you to understand the situations, the realities and all perspectives of people with disabilities and seniors in relation to not just this bill but any bill that's coming down from the present government. Consult, then create the legislation.

**The Chair:** Your time is up. I thank you all for attending for your presentation. I understand the written submission will be forwarded to the clerk of the committee

#### PATIENTS' RIGHTS ASSOCIATION, THUNDER BAY CHAPTER

**The Chair:** The Thunder Bay chapter of the Patients' Rights Association, Prue Morton, secretary. Welcome. You have one half-hour including questions.

**Ms Prue Morton:** The Thunder Bay chapter of the Patients' Rights Association is a grass-roots organization whose members have encountered a wide variety of health concerns. We appreciate the opportunity to appear before you, and while congratulating the government on the overall intentions of Bill 19, we would like to comment on certain aspects of it.

I'd like to say that it was only by luck that we heard this presentation was taking place. There was one small notice, I believe, in the paper, just after Christmas when a lot of people were away. That didn't even say what date it was going to be in Thunder Bay; it just said there were going to be hearings in Thunder Bay, or it would be one of the places. I've talked to quite a lot of people who said they didn't know this was happening at all. So I think the PR of the committee could be improved to let people know.

**The Chair:** You can blame me, ma'am, because we attempted to restrict—traditionally, some \$20,000 or \$30,000 was spent on advertising and I felt as Chairman that was a little much in the way of money and I did cut back on the advertising, so you can blame me for that.

**Ms Morton:** It may be a bit like from one bill to the other that goes from one extreme to the other a bit.

The purpose of the bill is to ensure that all people, particularly vulnerable people, can make their own fully informed decisions regarding their health and property, yet at the same time the bill has to afford protection to those who by reason of mental incompetence might endanger themselves or others. Obviously, these two objectives sometimes conflict and it is difficult to place

limits on either without producing many bureaucratic, legalistic and expensive safeguards. The old bill had so many of these that it was extremely cumbersome, but in some respects Bill 19 has too few.

The Advocacy Act was a good example of top-heavy bureaucracy, but to repeal it without putting anything in its place leaves too many people at risk and ignores the wide public input which preceded it. Vulnerable people are sometimes abused and do need more protection than can be provided by community advocates with very little power.

A vague promise that the Ministry of Citizenship, Culture and Recreation will work with such groups and that priority will be given to dealing with abuse and neglect of vulnerable adults is hardly reassuring given the present government's preference for *laissez-faire* policies. It was the inadequacy of advocacy provided by government operated or government funded programs which led to the enactment of the Advocacy Act in the first place. Systemic advocacy is particularly necessary and particularly difficult for individuals or small groups to address since institutions are hard-pressed to maintain reasonable standards with the present cutbacks in funding. Already what is deemed acceptable would probably not always be tolerated for their loved ones by those with enough money to seek alternatives.

Patients' advocates in Ontario's mental hospitals are now independent of those institutions and to fulfil their function properly this still needs to be the case. They have been able to bring about changes for the benefit of all their patients because being on the spot and independent they can see more clearly and press more effectively for change without endangering their jobs. In fact, there should be independent advocates in all hospitals and long-term-care institutions, although not necessarily one full-time advocate for each. These measures could well be incorporated in the bill, and judging by the former presentations here, maybe their training and mandate could include rights advisers as well.

Instead of one Consent and Capacity Board there should be numerous ones appointed, but only paid when their services are required. This would obviate the need for expensive travel and should make hearings quickly accessible. It would also make unnecessary the unsatisfactory provision that a board can operate with only one member and that it can operate without a member present who has experience in evaluation.

The new Health Care Consent Act is an improvement over the Consent to Treatment Act which it replaces. However, there are several more safeguards which need to be put in place. One is where the bill states that emergency treatment can be given without consent if that consent cannot be obtained because of a language barrier or disability, although attempt must be made to find a way of communication and there must be no reason to believe that the person does not need treatment. Guidelines need to be developed to ensure that the attempt is adequate and that the reasons for lack of belief are firm.

Another instance is permission for the health professional to perform a treatment without first obtaining consent if he or she believes that the treatment can cause little or no harm. Without safeguards, this vague state-



ment could be interpreted very differently by different professionals and sometimes the patient may receive psychological damage and other damage through the treatment which has not even been considered by the professional.

A third place in the bill which needs safeguards is where an evaluator may authorize an incapable person's admission to an institution without necessarily needing treatment. Relatives or neighbours may feel that frail people are not capable of looking after themselves safely and may persuade an evaluator to declare such a person incompetent, whereas in fact he or she is perfectly capable of deciding whether or not to take the risks of independent living. The power invested in professionals is apt to make them think paternalistically and therefore safeguards need to be in place to protect individual rights.

The ability of family members to become statutory guardians has been usefully enlarged by the amendments to the Substitute Decisions Act. We wonder if it's not possible to make provisions for non-related people to become guardians also under certain circumstances. For example, if a person has given power of attorney for property to a friend some time ago, when the power of attorney for personal care did not exist, and that person subsequently developed Alzheimer's disease or a stroke, for example, then in the absence of relatives that friend should be able to apply for the additional power.

Also, there are always going to be people who have not appointed anyone as their attorney and who unexpectedly become incapacitated and have no relatives able and willing to assume guardianship, yet some of these people will have devoted friends who could fill that role if suitable guidelines were developed, and sometimes they do know more than distant relatives.

Finally, safeguards need to be in place to see that these measures can be put in place quickly, without costing more than a low-income person can afford.

This bill should enable better treatment for a great many people. However, it needs a few more checks and balances and it should not be too difficult to add them. We hope that the government will agree and will take time to construct them carefully so that they do not prevent access to this treatment from being swift and efficient. That includes the amount of money it takes to challenge these things.

1040

**Mr Marchese:** Thank you, Ms Morton, for your presentation. This government has made it very clear—during the election as well—that it would repeal the Advocacy Act. It seems very clear now, unless otherwise stated by some of the government members, that that will remain that way and that the rights advisers are gone. I'm not quite sure how we convince the government members that we should restore some rights to individuals so as to make sure we protect individuals where there is a potential for abuse. I'm not sure we've been able to reach the government members so far, even though many of you have said over and over again that we need an Advocacy Act and that we need rights advisers.

Do you have any suggestions for the government members with respect to advocacy and with respect to

rights advisers, as to how we might convince them that perhaps we should restore some of those rights?

**Ms Morton:** As I said in this presentation, perhaps if they provided independent advocates who could also be rights advisers in hospitals—not necessarily one in each hospital because that might be economically impossible—they could prevent it perhaps in hospitals, at least. I'm not sure if it would overload it to make them available to the general public as well, but it might be possible that way. At least in cases like northwestern Ontario, where everything is so far removed from anywhere else, it would probably be a good deal cheaper to do it that way.

**Mr Marchese:** Sure. But a number of people have said this with respect to some of your suggestions: Under the Mental Health Act, they still retain the power to have rights advisers in that case, and that's good, on the one hand. On the other hand, they allow the hospitals to determine who would give that advice, and a number of people, including the Thunder Bay Regional Hospital people who were here this morning, said that that's a problem—

**Ms Morton:** Yes, it is.

**Mr Marchese:** —that it does constitute a conflict, and that should be addressed. There were some questions from Mr Klees with respect to that and how to deal with that. We think there's a possible conflict that needs to be dealt with. They should be independent. I suppose you're saying they should have a rights adviser in a hospital, let's say, whatever setting, but they should be independent from the hospital. Is that correct?

**Ms Morton:** Yes. It might be possible in a psychiatric hospital; I don't know the logistics of this, but it might be possible for the advocate to be a rights adviser as well, perhaps, which would mean one person instead of two, which would at least give people some independent resource.

**Mr Marchese:** Let me ask you something else, because this has come up often. What this bill allows is for paid caregivers to be guardians, and it gives priority to the caregiver over the public guardian and trustee as a court-appointed guardian. So we now have no rights advisers; we're not sure whether they will have them, in spite of what you and others say. We have no requirement to produce financial reports any more. We have the elimination of the restriction on the use of restraint. Does this clause worry you, that we would allow paid caregivers to become guardians?

**Ms Morton:** Yes, it does.

**Mr Marchese:** Can you tell us why?

**Ms Morton:** Really, you have said it very well; I'm not sure I can say it any better. If you're vulnerable, apart from anything else, you very often don't know about these things, particularly if you don't know there's any recourse that you can challenge it. It seems to me that a lot of very vulnerable people are not really in a position to know what's happening till too late.

**Mr Marchese:** That's true.

**Mrs Boyd:** On the issue of independence, the suggestion Mr Klees made about contracting with an outside organization and that solving the problem, we've had a model like that with the advocates for the developmentally handicapped, who were contracted, usually through



Family Services Association members but some other agencies, to offer that kind of advice. When we did the consultations in working on the Advocacy Act, many of those people working as advocates came forward to say they were in a conflict of interest when the agency providing services was their agency. It is a fairly complex issue, and we need to think very carefully about that.

Conflict of interest, whether it's the conflict of interest for health care professionals around wanting to provide what they regard as the best treatment despite what the patient says; or conflict of interest in terms of property, which is of great concern where there is property—often there isn't, but often there is; or conflict of interest when it comes to the emotional baggage that families may have, becomes a real issue. It's my sense that people don't really understand conflict of interest very well and how that can impact on a vulnerable person. Would you say that's true?

**Ms Morton:** I think that's entirely true. One of the problems is that a lot of safeguards were put into the old act, and they were so time-consuming and expensive that no one could lift hand or foot, practically, for ages, without spending a lot of money. Obviously, there's never going to be an ideal system, particularly in a legalistic society where everybody has to conform to the laws exactly.

**Mr Clement:** Thank you very much for your presentation and for your thoughts. It's very helpful to hear clear presentations such as the one you gave to focus our minds a bit. I want to cover a couple of things, some issues raised by your presentation.

I agree with you when you said the Advocacy Act created a top-heavy bureaucracy and that perhaps there are alternative ways of doing some good and achieving some justice. We are consulting with a number of groups, as many as we can, to try to come up with some creative ideas to do that. I thank you for your input on that.

I want to assure you that the Consent and Capacity Board can be regionalized—it doesn't have to be one big board—so there will be some opportunity for some regional input.

I also want to assure you that under the acts as presented, persons who are not relations but are friends can be made guardians, so it need not be strictly, in terms of hierarchy, a family member. So there is that possibility.

I want to come up a bit higher now and talk about the differing philosophical bases of dealing with this. Mr Marchese, in his usual way, has done an excellent job of presenting a particular philosophical view, and maybe he and I will just have to disagree. Having heard all the evidence the first go-round—because there was a lot of input into the Advocacy Act in the first go-round—there were two very clearly defined points of view. I do not mean to demean his point of view when I describe my point of view, which is that, by and large, friends and family who love the vulnerable person are able to deal in the vulnerable person's best interests in the best way; and by and large, persons who do not love that person, if they are part of the process, do not have the same stake, as it were, and might gum up the process rather than help the process.

1050

We're coming at it from that point of view. We want to give as much power as possible to the reasonable friend or family member who is acting in a reasonable way. But sometimes, as Ms Boyd has pointed out, they don't act reasonably. So what we need to do is set up a series of whistle-blowing techniques to ensure that in the minority of cases where vulnerable people are being handled in a terrible way, there are some checks and balances in the legislation. I want to get your comment on a particular section that may allay some of your concerns.

Under section 35 of the Health Care Consent Act it states very specifically—page 85 of the legislation, for those who are reading along—if I may paraphrase, that if the substitute decision-maker is making some very wrong decisions and the health practitioner is kind of scratching her head and going, "This is not in the best interests of the patient," that practitioner can appeal to the board. In fact, it says specifically in the legislation that the incapable person is a party to that appeal, so she's not cut out of the process if there's a bit of a bun fight over what's in the best interests of the patient.

That's just one example of a whistle-blowing section that allows a proper balance between the friend or family member who by and large loves the person but in some cases may not be acting in that person's best interests, and the health practitioner who's saying: "Wait a minute, this doesn't work. This is going to hurt the person, not help the person." Is that a way to look at this legislation that allays some of your concerns?

**Ms Morton:** It might be of some help, but if it were a property decision, it's likely that the practitioner wouldn't be involved at all, or quite possible they wouldn't be. There are several restrictions which have been removed; for example, any kind of vetting of the regulations that the person who's applying does have to be shown to be someone who really does have the person's interests at heart, and also that the witnesses have to specify that they believe the person to be capable for the power of attorney and so on. I think it just needs a few more regulations, which need not necessarily be very expensive, I don't think, to ensure that the people who are empowered are suitable.

**Mr Parker:** Maybe in that minute I can make one point, which is to reassure you on one concern you raised, and we've heard this concern before, about the capacity in the act to appoint a care provider as the substitute decision-maker. That causes you some concern, and we've heard it before, basically that we're putting the fox in the henhouse and that's where some of the trouble arises. The assurance I want to give you is that if a care provider is appointed as the substitute decision-maker by a court, the court has ultimate control over that relationship and the care provider is accountable to the court for the behaviour and conduct under that appointment. It's not quite as though the care provider is appointed and everyone walks away from the matter. There are very strict rules of accountability that would arise under those circumstances, and the matter would be appropriately supervised.



I just want to give you some reassurance on that point—because I recognize it's a concern you have, and we've heard it from others as well—that there is a strong line of accountability to the court when the care provider is appointed in that capacity.

**Ms Morton:** Yes. It's a rather legalistic accountability, though, and I doubt, if it were some kind of treatment which the patient wouldn't want and which the caregiver felt they had to approve because of conflict of interest, that it would ever come before a court.

**Mr Michael Gravelle (Port Arthur):** Good morning, Prue. I just want to mention that when we were aware the hearings were being held in Thunder Bay, our office, and I know Lyn McLeod's office as well, attempted to contact as many groups as possible. If our office didn't call you directly, I apologize, because we were trying to let as many people as possible know about the hearings being in Thunder Bay and wanted them to take advantage of the opportunity. I apologize if they didn't get to you, and we will next time. Thank you for all the good work you're doing here in Thunder Bay.

I apologize if I missed part of the discussion Mr Clement was having, but it's certainly an aspect that's been brought up, also by Persons United for Self-Help, PUSH: first of all, the definition of a blood relative, which probably does need to be defined; and the fact that there are many situations when a friend or someone you designate would be closer to understanding your needs and someone you'd be more confident with. I want to ask you to expand on the need for that, because the hearings are to try to bring together the best legislation possible to help people the most. My colleague—Elinor, I read somewhere that you said that even with legislation, often you don't find out until it's actually in legislation whether it's working, so obviously you want to get as close as you can when it's put in legislation.

This aspect is important, the concept of a friend being able to be in that position to be a Substitute Decisions Act person. I want to ask you to comment on the importance of that, and the definition of a blood relative.

**Ms Morton:** This happens particularly with elderly people, where a lot of their very close relatives have died and anyone who is related is rather distantly related and not in close contact. I know several cases where they have got a close friend who should have priority, but you need to make regulations about this so it wasn't just a question of relatedness but also some kind of—for example, I believe it's been cut out that they had to have been in contact with that relative fairly recently. I believe that doesn't exist any more.

**Mr Gravelle:** You could argue that it not necessarily even be in cases such as yours, but something that simply in terms of fairness should be in there.

**Ms Morton:** Yes.

**Mrs Caplan:** You raised a new issue that we haven't heard before, and it's hopefully one where the government will bring an amendment in. In the list of hierarchy, I think the point you're making is that where someone has designated an attorney for the purposes of property, that person should be considered before the public guardian and trustee for the purposes of guardianship. Is that correct?

**Ms Morton:** Yes, that's right.

**Mrs Caplan:** I think that would be a worthwhile amendment. It acknowledges that you thought about it before the law came in; maybe you didn't get around to—certainly if you've decided on someone for the purposes of an attorney under the Substitute Decisions Act for your property, it would be reasonable to assume, before you bring in the office of the public guardian and trustee, that that individual should be able to make decisions for you when it comes to personal care. It's a new concept.

**Ms Morton:** Yes. We have been in touch with people who have been in that situation, and they've said: "Why can't we be responsible for this? We are the people who were actually dealing with that particular person."

**Mrs Caplan:** Of course, it would be better if they executed a new power of attorney, but there are many people at this point in time who—

**Ms Morton:** It's too late.

**Mrs Caplan:** Exactly. I think that in the hierarchy, that would be a reasonable amendment.

You raised many things, and the one I'd like to go back to is the elimination of all the checks and balances. While Mr Clement read out one section for those people on treatment, I'm wondering whether you think the office of the public guardian and trustee should be able to question whether a power of attorney was made fraudulently or under compulsion. If there is evidence to suggest there is, there is nothing to allow the public guardian and trustee's office to investigate, even. Do you think they should be able to do that, to protect people who perhaps were coerced into giving a direction?

**Ms Morton:** It sounds like an excellent idea. I hadn't thought of it, but it sounds like something which would be really useful.

**Mrs Caplan:** It seems to me, if you're going to remove all those legalistic checks and balances, that where there is a question of coercion or of a power of attorney done in a really questionable way, at least they should be given the opportunity to investigate and seek out evidence from other family members or friends to overturn that. Right now they have no authority to investigate.

**Ms Morton:** And perhaps people could write in to the office of the guardian and trustee and say, "We have this concern." People have nowhere, really, where they can write in or phone and say: "Look, there is this problem. What do we do about it?"

**Mrs Caplan:** In fact, if you have no other place, that letter or phone call today does no good; they have no power to investigate, as I understand it.

*Interjection.*

**Mrs Caplan:** They do?

**The Chair:** Thank you, Mrs Caplan.

**Mrs Caplan:** I would like to have the question answered. Apparently the ministry says they do have the power to investigate.

**Ms Trudy Spinks:** Section 27 and section 62.

**Mrs Caplan:** That's under the Substitute Decisions Act? That's very helpful. Thank you.

**Mr Ron Johnson:** Great idea, Elinor. Thanks.

**The Chair:** Thank you, Ms Morton, for expressing your concerns before the committee.

1100

**Mrs Caplan:** I have a question that can be easily answered. Last week I asked who had carriage of this bill. I was told it was Mr Turnbull. I note that he is not—

**Mr Clement:** Tilson.

**Mrs Caplan:** Mr Tilson, as the parliamentary assistant. Where is he, and since neither he nor Mrs Johns is here, who is carrying this bill for the government? How do we get questions answered?

**Mr Parker:** I will, Elinor.

**Mrs Caplan:** Why don't you tell us?

**Mr Parker:** I just did.

**Mrs Caplan:** So you're carrying it in what capacity? As the chairman of a committee?

**Mr Parker:** I'm sitting in for David Tilson.

**Mr Clement:** Subbing in.

**Mrs Caplan:** Are you the sub on the committee or do you have carriage of the legislation?

**Mr Parker:** For all purposes of these proceedings, I'm David Tilson for the next two weeks.

**Mrs Caplan:** That is very unusual.

**Mrs Boyd:** Mr Clement is actually parliamentary assistant for one of the ministers involved.

**The Chair:** Yes, Mr Tilson is the parliamentary assistant, as you know, and he is on holidays.

**Mrs Caplan:** I understand that. I understand that Mr Parker is the sub for Mr Tilson on committee. I'd like to know who is carrying—

**The Chair:** He is not the sub. Mr Parker is a regular member of this committee, and he is carrying the legislation.

**Mrs Caplan:** He has carriage of the legislation on behalf of the government?

**The Chair:** Yes.

**Mrs Caplan:** Thank you. I appreciate the clarification.

#### ONTARIO MEDICAL ASSOCIATION

**The Chair:** Our next submission is from the Ontario Medical Association. Dr Warrack is the president of the Ontario Medical Association. He is accompanied today by Dr Ken Arnold, who is secretary of the Thunder Bay Medical Society, and Ms Barb LeBlanc.

**Dr Ian Warrack:** Thank you, Mr Chairman. I guess I don't really need to repeat what you just said, so I don't need to introduce ourselves.

The Ontario Medical Association represents Ontario's 23,000 physicians in economic and policy matters. We appreciate the opportunity to be heard by the justice committee today and express our support for the general thrust of Bill 19. Most of our comments will focus on the practical issues around consent to treatment, but we will also comment briefly on advocacy and substitute decisions.

I'll start my comments today by acknowledging that the current Consent to Treatment Act does the job the former government intended it to do. It creates a legal framework to protect incapable people from receiving dubious treatments from malintentioned health care providers at the behest of equally nefarious families.

Unfortunately, the government apparently believed that the way to deal with the bad apples, be they practitioners or families, was to cast a legislative net so wide that it would capture each and every encounter with an incapable person. Our experience suggests that this approach hasn't worked. In fact, it has created backlash in the broader medical community because the law is so blatantly anti-practitioner and anti-family. It is also highly impractical.

I'm hopeful that the new Health Care Consent Act will remedy these problems, and believe that one of the most significant amendments in the new act is the introduction of the purpose section at its start. While the Consent to Treatment Act has an underlying note of suspicion towards families and providers, the new Health Care Consent Act starts by outlining some very positive values. The OMA believes that the purposes of the act as set out in section 1 create a balance between patient autonomy on one hand and a patient's need for timely care on the other, a balance that is lacking in the current law. We are pleased that this balance between rights and needs is reflected throughout the body of the act.

The result is that Ontarians will enjoy access to a rights tribunal for a wide variety of purposes and the state removes itself from the doctor-patient encounter. The OMA strongly supports this direction and is pleased to see the removal of the rights advice provisions of the legislation and the repeal of the Advocacy Act. The OMA recognizes the need to assist vulnerable people and agrees that society should strive to enhance their autonomy and dignity. However, we don't believe the current system meets those objectives. We would encourage government to hold firm on its resolve to move away from a costly and adversarial rights-based system, and suggest that attention be directed towards systemic advocacy issues.

**Dr Ken Arnold:** There are a number of provisions in the current Consent to Treatment Act that make it unworkable in practice. I have not been involved in the legislative process for either Bill 19 or the previous legislation, but as a family physician here in Thunder Bay, I can state that my colleagues and I find the Consent to Treatment Act to be complex, intrusive and, in some cases, counterproductive to good patient care. In reviewing the new Health Care Consent Act, I notice several things that will help me provide good medical care within the bounds of the law.

The first is the removal of mandatory rights advice. Neither my colleagues nor I are comfortable with providing a US-style Miranda warning to our patients advising them of their rights. This is simply not appropriate within the doctor-patient relationship.

The second is the work done to clarify that minor variations to a treatment or a treatment plan are legal. This makes good clinical sense, and I support it. Similarly, I think the addition of the definitions for "plan of treatment" and "course of treatment" are a useful clarification, as is the exclusion of non-risky treatments from the definition of treatment. I also believe that acknowledging the right of substitute deciders to make decisions around withdrawal and withholding of treatment is useful and brings the law into line with common practice. End-of-life decisions are difficult for families and health care



providers in any circumstance, but they are made much more so by worries that one might be inadvertently contravening the act.

I am hopeful that the changes introduced to the consent scheme through the Health Care Consent Act, in addition to some of the positive features of the initial Consent to Treatment Act such as the hierarchy of substitute deciders, will enhance my ability to provide appropriate and timely care to my patients. Unfortunately, the current law has not been written with real-life practice in mind, and physicians have found it difficult to comply with its requirements.

**Dr Warrack:** In addition to solving some of the major issues of concern to physicians in their day-to-day practice, the new Health Care Consent Act fixes a number of smaller problems or omissions in the existing act. Examples include the de-linking of admission to long-term-care facilities with treatment, improvements in the substitute decisions hierarchy, changes regarding the Consent and Capacity Board, and removal of the rigid rules for the assessment of capacity.

I would now like to raise a few issues for the committee's attention. The OMA believes the introduction of the hierarchy of substitute deciders under the Consent to Treatment Act was very useful, and we believe it should be expanded to apply to all treatment, whether covered under this act or common law.

I am concerned by comments from some groups that government has introduced age limits for capacity into the act. Our reading of the law does not suggest this, and we would not support this notion. We believe it is important to preserve decision-making rights for capable adolescents. Another area of concern also related to treatment of young people relates to conflict between the Health Care Consent Act and the Child and Family Services Act. The conflicting provisions affect only a small number of adolescents, but these kids are very troubled, and even though they might be considered capable under the Health Care Consent Act, they are often lacking the insight necessary to begin treatment. We would ask that the Health Care Consent Act contain an exemption to treatment initiated under the Child and Family Services Act. This could be accomplished by removing subsection 84(2) from the act.

The next comments I'd like to make deal with the Substitute Decisions Act. The OMA is supportive of government's attempts to reduce the cost and complexity of the processes around powers of attorney and guardianship; however, we are still concerned that the capacity assessment process is unnecessarily bureaucratic. Many physicians are well trained to perform capacity assessments as part of their regular work. The week-long training required to become a designated capacity assessor under the Substitute Decisions Act serves as a disincentive for physicians to become involved.

A second issue under the Substitute Decisions Act involves the new streamlined process for activating powers of attorney for personal care. While the OMA supports this move, we wonder whether physicians will be expected to verify such documents and what the extent of their duty to inquire would be.

#### 1110

Our last point regarding the Substitute Decisions Act relates to the new provision which allows disclosure of patient information to the public guardian and trustee, capacity assessors and to persons who have made application to become a guardian. The OMA recognizes and supports the need for this provision in order to permit appropriate sharing of patient information but believes the clause should be strengthened to ensure that practitioners recognize that disclosure is at their discretion and relates only to information that is relevant in the circumstances.

In closing, the OMA would like to commend government for moving to make much-needed changes to the consent, advocacy and substitute decisions package. The OMA hopes that the introduction of clinically sound principles around consent to treatment will enable us to move beyond the paralysis created by the existing act to a new model that is designed to facilitate appropriate treatment while recognizing the rights of individuals to question decisions about their incapacity.

One final comment I'd like to make relates to implementation of the new laws. The OMA would urge government to provide the appropriate time and resources necessary for education regarding the legislation. There is bound to be confusion, and we need to try to minimize it to the greatest extent possible.

Thank you for your attention. We'd be pleased to answer any questions you may have.

**Mr Klees:** Thank you for your presentation. I would like to get your thoughts on a matter that several presenters last week and I believe Mrs Caplan as well suggested, that we should provide, by legislation, the requirement for colleges to implement specific guidelines with regard to rights advice. I'd like your comments on that.

**Dr Warrack:** As an association, we would prefer that the colleges would provide the guidelines for rights advice rather than it being in legislation. Barb?

**Ms Barbara LeBlanc:** In terms of the rights advice provisions, the first thing that we'd probably have to say is that a lot of our membership don't believe that physicians have a role to play in rights advice. The OMA hasn't taken a formal position, but generally the view is that as health care practitioners they're inclined to be spending their time providing care, not quasi-legal advice.

I suppose the other issue is, whether or not there's rights advice is really a political decision. If that decision is taken and rights advice is part of the scheme, then I think the OMA would rather see the College of Physicians and Surgeons responsible for setting standards than having a rigid legislative format.

**Mr Klees:** Just to follow up on that, can you be a little more specific for me? I think what we're trying to get at here is what your position would be. Would you be in favour of or opposed to legislation requiring the colleges to establish the guidelines and to enforce them?

**Dr Warrack:** Yes.

**Mr Klees:** I'm not asking the question right. Are you opposed to it or in favour?

**Dr Warrack:** Oh, sorry; in favour of the college being involved rather than it being mandatory under the act.

**Mr Klees:** You have no objection to a legislation requirement for the colleges to provide those guidelines?

**Dr Warrack:** No, I have no objection to that.

**Mr Klees:** Okay. I'd like to move on to another question relating to the definition of "treatment." There has been some concern expressed about the exclusion of treatment that in the circumstance poses little or no risk of harm. There was some suggestion that a practical way of dealing with this concern is perhaps to allow the physician to opt in to the act given certain circumstances. Do you agree that this would alleviate some of the concern around this definition of "low-risk treatment"?

**Ms LeBlanc:** What do you mean by "opt in"?

**Mr Klees:** In other words, right now the way the term "treatment" is defined, it actually excludes low-risk treatment. Under circumstances, it's been suggested that perhaps a practical way of dealing with this would be to allow the practitioner to opt in, to actually place himself under this definition.

**Dr Warrack:** You mean still—what?

**Mr Klees:** So he would still be covered under the act.

**Ms LeBlanc:** I guess it appears that what you're doing is giving the provider discretion as to whether or not they want to access the hierarchy and so forth. The way we've approached that is just a little bit different, and that is to leave the exclusion the way it's written and to suggest that in section 18, when you're outlining the hierarchy, you include not only treatments under this act but treatments under common law as well. Same idea; I guess a different approach.

**Mrs Caplan:** I appreciate the clarification. The concern has been raised that there's no consistent obligation. My view was always that it could be and should be the colleges which actually establish that, through standards of practice. However, one concern has been raised, and that is that social workers are not under the Regulated Health Professions Act, and so an obligation by providers to inform the patient that they've been deemed incapable and inform them of their rights would cover social work but would also allow the colleges then to establish that as part of their standards of practice under the Regulated Health Professions Act.

That was the debate and the discussion that we've had around here as to whether or not there should be that obligation for all providers. But as far as I'm concerned, there's never been an intention that in fact we should interfere with self-governance; I've felt we should not and that it should be the college's role to determine how to proceed to do that individually with the different professions. I wanted to clarify; there wasn't a question there.

I did have a question as it related to your concerns about privacy. We've had an assurance from the government that it will be bringing forward amendments that the privacy commissioner is recommending, which I think will address the concerns you have. However, you've approached it from the practitioner's need to have confidence about disclosure. One of the other concerns that we had was that it could be any person. I don't have a problem with disclosure to the office of the public guardian and trustee, because it's covered by the freedom of information and protection of privacy legislation.

Similarly, I think the assessors would be covered if they were connected with the PPAO, which is one of the reasons that I want them to be involved not only in training but also in supervision and coordination. The concern that I have is that anyone not covered by that legislation would have access to information, because I think that also would put the doctor or the provider in a terrible situation of feeling that the law allowed them to release it. So it's a safeguard to the providers.

**Dr Warrack:** As you may know from other bills, we have a little concern about privacy.

**Mrs Caplan:** Yes. My hope is that we will see those amendments before the end of the committee so that organizations such as yours would have an opportunity to review them and see if they do solve the problem.

Do I have time for one more question? Actually, there are two more if there's time. One was on what the effect would be of the removal of subsection 84(2), and that's a question for the government to answer, whether it would accomplish your concern or whether it actually goes further than that. So the question that I have for you has to do with the risk of harm. My concern there is that unless we see an amendment that would allow the act to apply where there is low risk and you don't have consent; in other words, on those—I think Mr Klees raised the issue. It's not whether the physician could opt in to the act, it's whether or not there could be a determination that the act would apply to those low-risk procedures, because I think you've foreseen what others have foreseen, and that is that where a person comes in and maybe is just fearful of even the most minimal, low-risk procedure, it could develop into something far more serious than that. I think that's the example of the unfortunate inquest that's being held.

I wondered if you'd like to just talk about that a little bit more and how you think that could be accomplished, whether the act should apply to everything or whether there's a mechanism that you foresee that would allow a physician to say, "Look, I think the act should apply in this case, and even though it's low-risk, we should have somebody here to help us"?

1120

**Dr Warrack:** I think it's very difficult to define what is low-risk. That's the biggest problem. Pretty well everything that we do—potentially, giving an Aspirin to somebody for some people is a risk. Walking across the street is a risk. So I guess the definition is or the real problem is to define "low-risk." We would presume that anything that we don't anticipate is likely to have a high incidence of adverse effects is probably—the problem is how intrusive is this going to be.

**Mrs Caplan:** That's the concern.

**Dr Warrack:** I know.

**Ms LeBlanc:** We're supportive of clause (g) in the exclusions list; I should probably state that straight out. One of the things that we saw (g) doing, and this is an example that we had through our offices—there was a nursing home resident who needed to have her ear syringed. It ended up being three phone calls: one to husband—husband wasn't available; called the son—son wasn't available. They somehow connected, heard that they both had messages, worried that there was something



dreadful happening to mom in the nursing home. Both called the nursing home and discovered it was for a syringing of ear wax. That's the sort of thing that the non-risky clause is meant to cover, as far as we can see.

**Mr Marchese:** I have one question and my colleague has another. I was trying to understand the vigour of your opposition to rights advisers. Before you comment, we heard this morning from Thunder Bay Regional Hospital—a mental health services manager, a psychosocial support person manager and a quality assurance risk management coordinator—and they were quite strongly supportive of rights advisers and felt that they needed to be there, as is in the act. We heard from Persons United for Self-Help, Northwest, talking about this. In fact she was very strongly concerned that we're losing, through this act that has been presented, some of the autonomy we were trying to restore to individual people—seniors and people with disabilities. We were informed by those kinds of people who were telling us that we needed to respect and be concerned about either individuals who had no family or individuals where family may have been the abuser, so we have to build in support for people like that. Why is that you're so strongly against rights advice for individuals where with people like this are now concerned we have totally shifted the balance once again?

**Dr Warrack:** One of the problems is that advising about rights in a physician's office is a very abnormal relationship, in that the formal way that it's done under the existing act seems abnormal. It just doesn't fit in with the normal doctor-patient relationship. On that basis, for every practitioner, I think, that formal mechanism strains the relationship. It's very difficult when you're talking about treatment to actually get into a legal discourse.

**Mr Marchese:** I understand. The way it was read and the way one person read it last week in committee, it was dreadful; I understand that.

**Dr Warrack:** I wonder who that was.

**Mr Marchese:** On the other hand, this morning, I think it was Sandi Homeniuk, the manager of health services, who said that was a bit burdensome, but there are ways we could have done the same thing. So do you agree that we could do it differently? Yes, it's strange to be reading it so technically and legalistically, as it seems, but the rights adviser is important. How we do it is the question.

**Dr Warrack:** We still think that during the doctor-patient relationship the advice about rights is not the way to go.

**Ms LeBlanc:** Just to expand a little bit, the one thing that we've learned about rights advice is that very few people actually go on and seek a hearing before the Consent and Capacity Review Board, and those people are in generally what we would call the grey zone of capacity. So it seems to us that the rights advice system isn't really targeting the frail and the most vulnerable; it's actually helping the people who probably least need the help. I think we'd rather see the scarce resources that we can devote to advocacy set out towards systemic advocacy and the broad issues around what's happening in various sectors; for example, the unregulated boarding homes, those sorts of things.

**Mrs Boyd:** I wanted to ask a question. You talked a bit about what is treatment and what isn't treatment, and what is low-risk and what isn't. We've had several people raise the issue of nutrition and hydration and how that fits into treatment or just activities of daily living. Certainly, when we think of anorexics or when we think of people who are in their last days of life, we see a contrast between the issues of nutrition and hydration. I wonder if I could get a sense from you whether you think that actually ought to be clearly defined as a treatment or not. I worry a great deal. We certainly have heard a lot about the withdrawal of nutrition and hydration without consent in certain circumstances, but also the force-feeding issue, particularly for disabled people who are saying they do not wish to continue. I think it's a very, very difficult, ethical issue, but when we're doing an act like this, I wonder whether it fits under treatment or just activities of daily living.

**Dr Warrack:** I think under certain circumstances hydration and nutrition in fact are the only way of handling a particular situation. So again, under some instances, you might well consider that as the only activity that's going on that's making a change to their being or wellbeing. In some instances, extreme instances, it could be considered to be a treatment, although most of us I don't think would assume that that's treatment. But it certainly doesn't follow our normal definition of treatment.

**Ms Boyd:** Certainly, one of the issues around all this is the reality that we're trying to protect vulnerable people, whether they're vulnerable because they're unable to express their own wishes and whether they may in fact be nearing the end of their lives and how do we keep them comfortable in those circumstances. But also, if we think of young anorexics and the decision very often to feed by tube, which is not accepted by that young person, we are getting into a very clear consent issue.

**Dr Warrack:** But a tube changes it, in my mind. A tube stops it. Then I would think—

**Mrs Boyd:** Then it's treatment.

**Dr Warrack:** I would say so.

**Mrs Boyd:** But offering food is the issue that was raised by one of the people last week, that food ought to be offered, whether or not it's accepted, just as a part of the activity of daily living.

**Dr Warrack:** Yes.

**The Chair:** Thank you, doctors, Ms LeBlanc, for your suggestions about possible clarifications in the act. That's very valuable to the committee.

#### FAMILY AND SERVICE PROVIDER ADVISORY COMMITTEE

**The Chair:** The next submission is by Ms Gillingham representing the Family and Service Provider Advisory Committee. Welcome. You have one-half hour, including questions. Please proceed.

**Ms Eve Gillingham:** I I won't take half an hour.

My first name is Eve and I am a member of the Family and Service Provider Advisory Committee. On behalf of the chair and other members of the Family and Service Provider Advisory Committee who could not be

here today, I would like to take this opportunity to thank the standing committee on administration of justice for the opportunity to speak to Bill 19 today.

Before I begin my presentation, I think it would be helpful for this committee to know a little bit about the Family and Service Provider Advisory Committee, to hear our views in context, because the FSPAC, as it is known by its acronym, is a relatively new committee. It was established in April 1995 in accordance with the provisions of section 11 of the Advocacy Act. According to the legislation, FSPAC was created with three main purposes: (1) to comment on the impact of the advocacy services provided by the commission on the families and providers of health and social services of vulnerable people; (2) to advise and consult on the policies and procedures of the commission as it carried out its legislated mandate; and (3) to appoint two members to the Advocacy Commission's complaints review committee which would, if necessary, deal with complaints about advocates.

1130

We are required to report annually to the minister, now the Minister of Citizenship, Culture and Recreation.

We are a small committee composed of five members and a chair. Three of us represent service providers and three of us represent families. I am a nurse by training and I have been involved in direct care and supervision for more than 15 years. I have worked in acute care settings, long-term-care facilities and other institutions. The other service provider members of FSPAC include a hospital administrator and the manager of policy for a provincial mental health association. The family members of our committee include the father of a multihandicapped daughter, the mother of an adult schizophrenic son and the son of an elderly mother suffering from Alzheimer disease. We come from all parts of the province: from Toronto, Brockville, Windsor, Dundas and Thunder Bay.

Since our inaugural meeting in April, we have held five meetings. In a relatively brief period of time we've determined how we would operate, we established a cordial working relationship with the chair and staff of the Advocacy Commission and we began developing contacts outside of our respective institutions and organizations in order to carry out our mandate of gathering information on the impact of the commission's activities on families and health and social service providers. Last month we participated in a focus group session organized by the ministry.

Although FSPAC is a relatively young committee and its brief history will likely go unrecorded if the Advocacy Act is indeed repealed, we FSPAC members nevertheless would like to raise our concerns about Bill 19. Through our personal and professional lives, we represent many decades of expertise and experience in providing service, care and support for vulnerable people throughout the province of Ontario. We represent the many professionals, parents, children, partners and friends involved in the lives of vulnerable people.

Because of FSPAC's mandate, my remarks today will deal primarily with the first part of Bill 19, the repeal of the Advocacy Act.

We sympathize with the government's struggles to rein in the deficit. Nevertheless, we strongly recommend that the government not repeal the Advocacy Act unless and until some other independent system of advocacy is in place throughout the province. We believe that it is the obligation of government, not just families, service providers and volunteers, to offer support for advocacy so that the rights of vulnerable people in Ontario are respected and vulnerable people are able to make their own life decisions. Over the past 15 years, it has been demonstrated again and again that there is compelling need for a system of independent advocacy in Ontario. Please ensure that the work of the past decades will not have been wasted.

As family members and service providers, we play an important role in advocating on behalf of vulnerable people and assisting vulnerable people to advocate on their own behalf. However, there are limits to what we can do. We cannot be there for every vulnerable person. While most families act as powerful advocates on behalf of their vulnerable family members, there are unfortunately some families that are either unable or unwilling to care for their vulnerable family member. In some cases, even caring families may sometimes burn out as a result of being pushed beyond their ability to cope, and reluctantly they sometimes abdicate their responsibilities.

You must also recognize that there is the potential for conflict of interest between what the family and vulnerable person or service provide and vulnerable person consider to be in the vulnerable person's best interests. In addition as service providers, we sometimes find that our organizational or professional goals are in conflict with our ability to successfully advocate on behalf of the vulnerable person. From my own experience, I know of health care professionals who have had their jobs threatened as a result of trying to advocate on behalf of a patient. Therefore, we believe that it would be best to avoid any situation that may pose a conflict of interest.

As for relying on volunteers to act as advocates for vulnerable people, it is true that there are many willing and capable volunteer advocates working alongside paid staff in a variety of facilities and community agencies. However, volunteers come and go. Before they can be effective, they need to be trained. Once they are trained, they may burn out. Community agencies are also a source of advocates, some of whom are paid through government funding and through other funding sources. However, as these agencies experience cutbacks in funding, their staff is increasingly overworked and, as you know, underpaid. Consequently, waiting lists for community services continue to be long.

Advocacy for vulnerable persons, we believe, requires the government to take two approaches:

Individual advocacy with a primary focus on promoting self-advocacy, as well as encouraging such models as the personal support network or circle of friends for those who cannot advocate on their own behalf, and to protect the vulnerable from abuse;

Secondly, systemic advocacy, which offers the possibilities for broad change at the provincial level that will benefit all vulnerable people. We recommend a cross-disability approach. After all, every vulnerable person



needs shelter, transportation, sufficient income to cover his or her basic needs and so on.

Systemic change can make a difference for not just one vulnerable person, but for all. It also decreases the need for individual advocacy services.

Allow me to offer an example of a systemic problem that came to the attention of one of our members last week. The problem occurs with transportation that requires a wheelchair going from Hamilton to Toronto or from Toronto to Hamilton. GO Transit has an exclusive licence to carry wheelchair passengers on this route, but the station in Hamilton is not wheelchair-accessible. Apparently, the Hamilton station will be refitted at some unspecified time. At the same time, there are Greyhound buses that have been modified to take wheelchairs, thanks to large grants from the federal government. They do not make a stop in Hamilton en route because Go Transit has the exclusive licence for this route. It seems that buses are not allowed to carry wheelchair passengers from Hamilton to Toronto or from Toronto to Hamilton.

Just this week, our committee member checked back with the bus company about the possibility of stopping in Hamilton for a wheelchair passenger. When pressed, the company official agreed that a special stop could be made for a wheelchair passenger, but if there was another bus on the platform, that there would not be enough room to use the lift and the person in the wheelchair would have to stay on the bus. There must be a solution to the problem, but there does not seem to be any united effort or any coordination in addressing the issue.

In addition to coordination, much of what is required for successful advocacy involves training and support:

Rights education for clients of service or care facilities, as well as for families, friends, care/service providers and volunteers;

Education about treatments, types of residential facilities and caregiving services and supports;

Ongoing assistance to families, caregivers and volunteers in caregiving, and for volunteers, in particular protection from liability;

Knowledge about where to raise concerns about care or service, and how to be an advocate for oneself or another person; and

Ongoing professional development for caregivers on rights, complaints, newly introduced legislation, regulations and procedures.

If the Advocacy Commission, as it exists today, must be dismantled because of financial considerations, we recommend that the government consider funding a less costly entity: one that is at arm's-length from the government, one that has broad representation from a variety of disability and seniors groups, one that could act as a coordinating body.

This would, in turn, offer policy advice on issues affecting the vulnerable:

To ensure that essential advocacy assistance be made available 24 hours a day, seven days a week, as required;

To encourage the involvement of volunteers working on behalf of vulnerable people, but not to the exclusion of paid staff. For example, a corps of regional facilitators could not only train volunteers, but they could address the need for local accessibility to services and advocacy,

focus on local issues using local resources, as well as address the need for accountability for the quality of services provided;

To make available information pertaining to advocacy in a variety of alternative formats to address some of the barriers obstructing the provision of advocacy, such as education level, speech ability, comprehension, language and culture of the vulnerable person;

To offer the possibility of flexibility in advocacy, depending on the particular circumstances and/or disability of a vulnerable individual;

To provide opportunities for consumers to dialogue and consult with care and service providers that allow for all of their concerns to be raised and, hopefully, addressed;

To make any complaints system both easily accessible and user-friendly;

To ensure that confidentiality be respected for those seeking advocacy.

Above all, we ask you to ensure that independent advocacy and rights advice are provided consistently through the various pieces of legislation.

#### 1140

We also believe there is valuable information available from the Advocacy Commission, information that should not be lost. For instance, the statistical data collected by the Advocacy Commission on rights advice, as well as intake and referral, would prove useful to any future advocacy entity—for example, how much demand for advocacy services occurs after normal business hours—and it may be economical to build on the Advocacy Commission's existing database that is used for intake and referral. This database of care and advocacy services could be maintained and updated and perhaps made available on CD-ROM through public libraries. We recognize, of course, that resources will be required to keep such a system up to date.

We urge the government to offer key leadership as well as ongoing support and resources in retaining comprehensive legislated advocacy. We further urge you to use your government powers immediately to improve the situation for vulnerable people in this province: Ensure compliance with existing legislation and regulations that affect vulnerable people; consider individualized funding for people with disabilities who do not fit the criteria for specific programs—in other words, focusing on client needs rather than on program needs; and consider offering support for Ontarians with the Disabilities Act.

Finally, after all of your considerations, should you decide to repeal the Advocacy Act, we ask you to create a bridge between existing services provided by the Advocacy Commission and whatever plans the government intends regarding advocacy, to ensure that all vulnerable people in Ontario will be protected and that no one will ever again fall between the cracks.

Thank you. I would be more than pleased to entertain any questions.

**Mrs Caplan:** Thank you for an excellent presentation. I think that your suggestions for what could be put in place are reasonable and realistic and I hope that the government will listen. The Australian model—I don't know if you're familiar with that.

**Ms Gillingham:** No, I'm not.

**Mrs Caplan:** In Australia, they have three advisory committees which deal with the policy issues and an opportunity for cross-dialogue. One policy committee is for professionals, one is for families and providers and the third is for consumers and patients. The three advisory committees act in a way that helps with policy development, pointing out where the legislation is in need of improvement. In the annual report of their consent and capacity board, they notify the government of suggestions that have come forward, so it goes beyond their quasi-tribunal role and it also allows for a vehicle. Because they have a coordinating role as well, they can refer to identified community advocate organizations or just answer questions. They have a mandated education role, and I noticed that you recognize that.

Just as something to explore and look into, would you support that kind of compromise between nothing and something?

**Ms Gillingham:** Yes, I would.

**Mrs Caplan:** Do you think it's at least a good idea to look at what's happening in Australia? It's my understanding that it's relatively inexpensive, that it's a way to have a foundation so that not all advocacy services are lost and that you do have the opportunity for education. So you would support that?

**Ms Gillingham:** Yes, I would.

**Mrs Caplan:** The other point you make that I think is an important one is consistency. We know that is lost in the legislation, because individuals are informed of their rights only under the Mental Health Act if they are presently, under this new legislation, in a facility. The consistency that we're looking for, the minimum, is that they also be informed when they are found incapable and know what their rights are under the Mental Health Act, no matter where they are.

I'm suggesting, actually, that the definition be changed from facility to program, so instead of being a psychiatric facility it would be a psychiatric program, and that would encompass all the schedule 1 and community hospitals, plus community-based mental health programs. Would you support that kind of an amendment that would allow for consistency?

**Ms Gillingham:** Yes, I would.

**Mrs Caplan:** Similarly, I believe the issues of confidentiality will be addressed by the privacy commissioner and I hope those amendments will be tabled in enough time for us to review them before clause-by-clause.

The last point I would make is the consistency of the providers having an obligation to inform an individual when they have been found incapable. There's no consistency right now among the colleges, and we know that social workers are not under the Regulated Health Professions Act. Would you support a statement of obligation that would be consistent to ensure that all providers, whether they're under the RHPA or not—

**Ms Gillingham:** Absolutely.

**Mrs Caplan:** —and that that obligation would be to inform of a finding of incapacity, to inform of the right to appeal and how to appeal?

**Ms Gillingham:** Yes, I would.

**Mrs Caplan:** Those are the three. Thank you very much for an excellent presentation. Was your group consulted by the government?

**Ms Gillingham:** No, we weren't.

**Mrs Caplan:** You were not. Just to put it on the record, I did ask the Ontario Medical Association if it was. Their staff was consulted, although they did not have a meeting with the minister on this.

In the time remaining, could you tell us a little bit more about the Ontarians with Disabilities Act? I haven't heard of that legislation. It's on your page 7.

**Ms Gillingham:** Actually, I inquired, because this paper was composed by a number from our group. What it is is an act that has been proposed to protect the rights of disabled people with regard to their employment.

**Mrs Caplan:** I see.

**Mr Dwight Duncan (Windsor-Walkerville):** Is that taken from the Americans with Disabilities Act? Is it intended to act as that statute of the government of the United States does?

**Ms Gillingham:** I'm sorry, sir, but I can't answer your question.

**Mr Duncan:** I think it does. I think it has been proposed and is very similar to that law.

**Mrs Caplan:** If you find out what it is, you can just let us know in writing to the committee and it will become part of the record.

**Ms Gillingham:** Okay.

**Mr Marchese:** Thank you for your presentation. This government has been very clear about its desire to repeal the Advocacy Act. They were clear before and they're very clear now. They're not very clear about what to replace it with, if indeed they're going to replace it with something. My sense is that we're not going to get much of a replacement with respect to advocacy or the work the Advocacy Commission did, was about to do and so on. It eliminates the rights advisers as well.

You made a number of very interesting points, and you haven't been the only one who has been saying it. There's a recurring theme with respect to what you're saying. Just to repeat, some of the stuff you've said is: "We believe that it is the obligation of government—not just families, service providers and volunteers—to offer support." I agree with that. I think this government takes a different position, but many of us take the position that government has an obligation to provide support in this particular field. I agree with you that there should be independent advocates in Ontario.

You talk about some of the difficulties with family members taking care of individuals. Some are very caring, of course, but some, you say, may not be prepared to do the caring or are incapable of doing the caring, and some don't have families, so how do you protect those individuals?

You also said you know of health care professionals who have had their jobs threatened as a result of trying to advocate on behalf of patients. That's the first time I've heard that from any submission, but that's a reality as well that complicates advocacy in general. Even those who could potentially be doing it in some cases are threatened by their employers about doing that.

**Ms Gillingham:** That's true.



**Mr Marchese:** You talked about volunteers, not that you're opposed to volunteers, because they're there and you welcome them, but that they need training, they need a great deal of support to be able to do that work, and eventually they leave. I'm not quite sure how we deal with some of your suggestions, except that I support them. I supported the commission. I support the rights advisers because it gives protection to individuals who otherwise may not get it or may not have it.

1150

Do you have any other suggestions to the government members with respect to advocacy or rights advisers in terms of restoring that, or can you find a way to reach some of the members perhaps?

**Ms Gillingham:** Gee, I'm not sure I can do that. Upon review of the Advocacy Commission, I'm sure you're aware that it was composed of 13 members. Eight of those members represent essentially the province of Ontario through their disabilities, their locations, their cultural aspects as to how they actually receive their physicians within the community. I think if it was going to be considered that there be a group of people who represent those disabled, certainly there is a core group that has been established.

**Mrs Boyd:** I want to go back to the two issues you raised about, first of all, the vulnerability of someone within the health care professions in advocating on behalf of patients. We talk a lot about team providers, but we all know that even under the Registered Health Professions Act, everybody works under the physician. I certainly, during the time we were talking about how to do advocacy in Ontario, heard from many nurses in particular, working often in home care situations, who were concerned about the care that was being given to people and, because the physician did not agree, were not able to make those wishes known. I think that happens in many other settings as well. We've heard about it in nursing homes.

Part of the issue in this whole rearrangement and ensuring there's advocacy is somehow getting beyond those professional protocols, if you like, about who is able to speak to whom about what. That never seems to come out, so I'm glad you raised it, because I think it's a very real problem and certainly it's not one we've heard thus far in the committee. I'm very glad you raised it. I can think of three instances myself where a VON nurse in one case, a nurse in a long-term-care facility and a nurse in an acute care hospital had disciplinary notes on their records because they went around a physician because of a real concern about the wellbeing of their patients. I think that's a real concern, and I'm awfully glad you got it on the record.

The second thing is the fatigue aspect, caregiver fatigue in terms of families. One of the real issues around long-term care is the issue that you may have a willing and loving family, but 24 hours a day, seven days a week, often for many years, becomes a very real problem for many of those families. I think in looking at both long-term care and this act, we probably haven't made enough recognition of how those well-meaning families become unable to give the kind of care that they started out to give as that fatigue comes forward.

I'm glad that you mentioned that, and for volunteers as well, the burnout issue. It is a very real issue when we look at these kinds of things. People's lifespan is often longer than was expected initially, for example, or the care becomes heavier than was initially expected. It puts a real burden on families that hasn't been recognized, and that makes people more vulnerable.

**Ms Gillingham:** Very much so.

**Mr Clement:** Thank you very much for your presentation and also for participating in the focus group which you mentioned in your presentation with respect to the Ministry of Citizenship, Culture and Recreation and some of our attempts to have a dialogue with interested parties about, in the absence of an Advocacy Act, how and in what manner government can concern itself with this area. I just want to thank you publicly for participating.

**Ms Gillingham:** I think I should interject at this point. I missed that particular meeting. We had a large dumping of snow here in Thunder Bay, so that was the one meeting I did miss, but it did go on.

**Mr Clement:** Let me thank you institutionally then, for participating, rather than personally.

**Ms Gillingham:** All right.

**Mr Clement:** I did want to touch on a couple of aspects of your presentation. I want to return to something I said last week in terms of my reading of the O'Sullivan report, which really has been a touchstone for many of the groups we heard last week in regard to how to orient oneself with advocacy. I found it very compelling, upon reading sections of that report, that Father O'Sullivan was talking about the general moral duty of human beings to always, to the best of their ability, act as advocates for their fellow citizens who were vulnerable.

Last week I expressed my concern that if we have a whole hierarchy and bureaucracy of government involvement, we would be detracting from that, because there does tend to be a tendency sometimes, when people see government involved in something, they think that everything's all right and they don't think they have any more personal responsibility for that particular aspect of society. I would be concerned about that.

Related to that—and I would like your response to this line of reasoning—our view is that rather than being a conflict of interest, it is precisely those who are the most knowledgeable and the most concerned about the vulnerable person who make the best advocates, whether it be a family or friend or health practitioner. Those persons seem to be the most connected to the vulnerable person. I'm not saying they always act perfectly, and there have to be safeguards, but by and large, that would be the case.

I would put on the record again, we as MPPs, whenever we go back to our ridings, constantly deal with situations where our constituents are coming to us because the state has acted in an uncaring, unthinking way which genuinely hurts them and their family. I would put it to you that we have no guarantee—in fact quite the opposite of a guarantee—if the state concerns itself with vulnerable persons in vulnerable situations, they might make a mess of it to a far greater magnitude than those who love or are knowledgeable about a vulnerable person.

Am I barking up the wrong tree in thinking that way, or is there a way to reconcile what you've been saying with what I've been saying, do you think?

**Ms Gillingham:** No, I think there cannot be an exclusion of any group, whether it be a volunteer group, a government group, a nursing agency, a physician group. We all have an obligation to our vulnerable population.

**Mr Clement:** Do you share my fear—I sense that you don't and I'd like you to explain why—that the more we have state-sponsored advocates, state-sponsored advocacy commissions, the more we're getting away from those who are knowledgeable or who love the vulnerable person? You don't share that concern.

**Ms Gillingham:** No, I do not.

**Mr Clement:** Can you elaborate on that just a bit?

**Ms Gillingham:** I think when you speak of state, you're elected by all groups of people, whether they be vulnerable or well, and when you have their best interests at heart, you've listened to them. So why would I have a concern about the decision? Hopefully, you've made a very knowledgeable decision based on facts and data as opposed to emotions and feelings.

**The Chair:** Thank you, Ms Gillingham, for your presentation.

The room will be secured, if you wish to leave your documents here, and will be open at 1:20. We are recessing to 1:30.

*The committee recessed from 1158 to 1335.*

**The Chair:** I call the meeting to order. It would seem that the 1:30 and 2 o'clock are not here yet.

**Mr Len Maki:** We're here, sir. I'm here for 1:30.

**The Chair:** You'll have to step down until we do the third one then, if you would. She's already at the table

#### AIDS COMMITTEE OF THUNDER BAY

**The Chair:** Then 2:30 is the AIDS Committee of Thunder Bay and we have before us Sheila Berry, the support services coordinator. Ms Berry, you have one-half hour, including any questions that you might wish to answer. You can proceed.

**Ms Sheila Berry:** You'll have to excuse me. I'm operating with a cold.

Mr Pius White, who also had a lot of input into the information that you're going to get, is a person living with AIDS. He tried to be here, but he's ill this morning so he's not able to be here. Hopefully, I can do a good job of representing his interests too.

I work at the AIDS Committee of Thunder Bay. Many of the people I work with may or may not have health care directives done in advance, so a lot of the time we, as support workers, will work with them and advocate to make sure that they get a good level of care because there is still a lot of misinformation and unacceptance of the disease, mainly in how the disease is transferred from one person to another. Having said that, this is why I'm very interested in presenting to your committee.

I'm just going to read some of my stuff and I may add some stuff as I go. If you have questions, that's fine.

Having reviewed Bill 19, we realize the impact it will have on a person's right to determine the direction that their personal health care will take if a health care

directive or living will or power of attorney is not in place before that person becomes unable or is deemed incapable of making decisions. We are therefore proposing the following recommendations to allow all persons the right to self-determination regarding their own care.

The first point is that we would ask that you rethink your position on the Advocacy Act and not repeal the act in its entirety because there are many good things proposed by the Advocacy Act that do ensure that an individual who may be vulnerable will therefore get the level of care they need and also be informed properly at each step of the way. The purposes and principle upon which the act was based do encourage empowerment of vulnerable persons and do respect their rights, freedoms, autonomy and dignity. That's very important.

We ask that you provide advocacy services in some mechanism when you're rethinking Bill 19, to have something in there where there are avenues for advocacy and a recognized advocacy person in the community or in the institution who again will ensure that the rights of the individual are looked after properly. If the proposed methods outlined in the act are not feasible and are confusing, then we ask you to rethink them and make the necessary adjustments.

#### 1340

A rights adviser is a must to ensure objectivity and fairness to persons already marginalized and systemically discriminated against. In those people, we include aboriginal peoples we work with, people who are drug users, gay and bisexual men and women, transsexuals. We may be working with all kinds of different people, handicapped people. Where empowerment was encouraged through the Advocacy Act, it seems now that it's on the flip side, and that's not a comfortable position for many people whom I work with.

Involve people affected by the proposed legislation at the committee level. Get their input, find out what works, work with them. They have good brains and life experience that can add and help and make a good comprehensive package that we can all live with.

Point 3: As I mentioned before, parts of Bill 19 take power for decision-making out of the hands of the affected individual and encourage dependence and disempowerment. How it does that is, when you bring people into the decision-making process who do not have an established, long-term relationship other than a family by blood or by marriage—there could be an estranged, long-term separation from the family of origin and there could be people at the community level who would have more information and know what more this person who is requiring treatment would like.

It may be totally inappropriate for a relative or family member to intervene in personal care if the affected person does not wish it. In the case of estranged family ties, there has not been the continuity of relationship and communication between the two relatives. Therefore, the substitute decision-maker may have no idea what the incapacitated person may want. There may be deep-rooted differences and resentments present that will in themselves affect the decision-making process. We cannot assume that the person making the decision in these cases will have the best interests of the incapable person at



heart, whereas a friend, roommate or other significant person may know the incapable person very well and be aware of their wishes with respect to health care.

In situations where the family has not been supportive or respectful of a person's lifestyle choices, how can a relative or family member put aside their personal prejudice to make an appropriate choice for the incapable person? There could be a lot of very strained relations. I see it every day. When we have a person living with AIDS, on one hand, who has chosen the life they have, they're entitled to the same level of care, although we as support workers try to work with the family unit and to mend, to heal, to do this, usually by the time a person comes home to their community. In some cases, they choose to the community of choice which may be, for instance, the gay community in Toronto. There is a very close-knit community and they're very supportive of each other and provide care and support for each other.

Sometimes what will happen is, those old wounds, those strained positions, those sort of polarized views about lifestyle can affect and can be more damaging than someone who lives closely with the person or around the person and that person's network and would know more what the person wants and be able to carry it out without those engrained prejudices, biases, whatever you will.

This in fact could add more stress to the person's recovery. If a choice was made or the family was making decisions and—let's take a wild case where, for instance, someone is gay and it could be an ex-partner who comes to support the person, and the family is not in tune or does not agree with the lifestyle. They may try to disbar that person who could offer a lot of support emotionally, psychologically. That could be very damaging to the person's recovery mentally, emotionally and psychologically, so somehow we have to have a balance there.

Like I say, we always try to work with the opportunity to bring families closer together, but when someone is dying that's not always first on their mind. Sometimes people can't put those things aside until it's too late.

On point number 4: Bill 19 favours relatives and family over relationship and community. In the case of close-knit and supportive communities in which the individual may reside, care must be taken in choosing who might be the most appropriate person to represent the best interests of the incapable person. There must be guidelines in place to ensure that the vulnerable person's right to appropriate decision-making is ensured. I would ask that you think about that when you are redoing Bill 19. There are a lot of good things in Bill 19 that I like, one of them being the process of appeal and the process of advocacy. However, without a rights person in there somewhere to intervene, we need to take that into account. I think the two can be worked out somehow.

With the abolition of the Advocacy Commission, how will the rights of the incapable person be guaranteed? We urge you to think about how this can happen and incorporate this into the proposed Bill 19. Having come so far to ensure that all Ontarians are entitled to assert their rights, what mechanisms are there to guarantee that this will happen without a body to oversee this? That's a question that I put to the committee and to our current government.

Regarding the Substitute Decisions Act, will the existing power of attorney kits still be used to indicate a person's choice of power of attorney for personal care and continuing power of attorney? Can anyone answer this for me?

**Mr Klees:** Yes.

**Ms Berry:** Yes, they will? They're still using the kits? There's nothing to replace them?

**Mr Klees:** No.

**Ms Berry:** Thank you.

Regarding the power of attorney for personal care, are there any changes in who can and who cannot be named? There's very specific information in the Substitute Decisions Act. It specifies that the following persons cannot be named: a person who is 16 years old or more—wait, is that a mistake? "Sixteen years and under" that should be—cannot be named; so 15 and under. A person who is providing you with health care or residential care, social, training, advocacy or support services for compensation—are there are changes as to—

**Mr Parker:** The answer I'm getting is just advocacy. Basically it's the same list but with some minor adjustments.

**Ms Berry:** That could be a problem then, because if there is no provision for advocacy in this particular section here—part of my job is advocacy. Part of my job description is advocacy so if I could know what the changes are, that would help. This was a question that Mr White wanted to know because he's in a situation right now where the best person to advocate for him would be his support worker, who knows him and has done his health care directive with him. So we want to know if there are going to be possibilities there.

**Mr Parker:** Did you want the response now? One of the concerns we're receiving is precisely the other side of that argument, that those people who are in a position of care have that degree of control over the person, and there's the concern that they might exercise that control against the interests of the person. So that's the consideration that has to be balanced off in that discussion.

**Ms Berry:** Perhaps there could be a way to set out some criteria, if that were to be allowed.

1350

**Mr Parker:** We will get into an opportunity for dialogue later on. I don't know how you want to use your time, but those issues can be addressed.

**Ms Berry:** Okay. I've never done this before, so I don't know.

Bill 19, part II, Health Care Consent Act. Under the existing act, if consent to treatment is refused on an incapable person's behalf by the authorized substitute decision-maker, the health practitioner may treat despite refusal, only if the decision-maker did not comply with the principles set out in the act. In the new Health Care Consent Act, the practitioner may treat the incapable person at his or her own professional discretion even if the authorized person refuses treatment in compliance with the principles of the act. Is this true? This is how I read it. Maybe we can save that till the end.

**Mr Marchese:** You only have half an hour, and we may not have a chance to ask too many questions, so if you want the members or a ministry person to answer

your questions, maybe you should decide that, because you won't have much time left. If you want answers you should just indicate that as you go along.

**Ms Berry:** Yes, I do. I would like an answer to that, please.

**Mr Parker:** Could you repeat the question?

**Ms Berry:** It's right in number 8, put as a question.

**Mr Marchese:** Mr Chair, can I recommend that the ministry people come forward to the table, closer to the parliamentary assistant, to provide that advice.

**Ms Halyna Perun:** My name is Halyna Perun. I'm legal counsel at the Ministry of Health.

Section 15 of the Health Care Consent Act says: "If after consent to a treatment is given or refused on a person's behalf and the person becomes capable in the opinion of the health practitioner, the person's own decision to give or refuse consent governs." Therefore, even if you have substitute consent and the health practitioner is treating on the basis of the substitute consent, when the person becomes capable, this act clearly says that the health practitioner should take the consent or the refusal of the capable individual.

I think there was a section like that in the Consent to Treatment Act. There may have been just some minor word clarification to make sure the intent is accurate.

**Ms Berry:** As I read it, I had a different perception.

**Ms Perun:** So is that clearer?

**Ms Berry:** No, but maybe I could find out the answer to that.

**Ms Perun:** I can speak to you later if you'd like.

**Ms Berry:** That will be fine.

**Mr Parker:** My problem is with the question. Once we've got the question clearly understood, we'll get you the answer.

**Ms Berry:** It's clarified in number 8.

What if the health care directive clearly states refusal of the procedure or treatment? Because of the number of opportunistic infections with which a person may be infected, and because many treatments and drugs are not proven, a person may not wish to continue aggressive treatment. Is this allowed? I'm feeling vague about what I read in the new act. It's allowed?

**Mrs Boyd:** Yes.

**Ms Berry:** Even if the person is incapable and the substitute decision-maker makes that decision based on written evidence in the health care directive?

**Mrs Caplan:** The directive takes precedence. That's why people should be careful how they write the directive. It's very important that people know they must be very careful about how they write a directive, because the advance directive takes precedence. The only time it can be challenged is if the substitute or the attorney believes there's new information that would govern a wish different from the directive. They can go to the capacity board to make their case, but even then, a lot of weight is given to the advance directive. That would be in the case of a new cure.

**Ms Berry:** Yes, or a new treatment.

**Mrs Caplan:** Or a new treatment that was not known when the directive was made.

**Ms Berry:** Also, if a Do Not Resuscitate order is on the health care directive, can a health care practitioner overrule this?

**Mrs Caplan:** Again, be very careful. If it's a blanket Do Not Resuscitate, it may not be in the event of a terminal illness; you may have an arrest in a person who could regain full consciousness and awareness and full use of their body and independence and so forth. It's important for anyone when they write that to contemplate under what circumstances they would want a DNR.

**Ms Berry:** Thank you. This was a question from Mr White. That's the gist of my presentation.

**Mrs Boyd:** What your presentation has made very clear is how very important it is going to be for the AIDS community to educate itself and its members about the importance of the personal health care directive and having a power of attorney, particularly, where we do know there often is a conflict between the family's values and the person's values around lifestyle and around choices, that it's important for people to do that. We understand it's very difficult to talk to people about that and to help people understand the complexity of this whole thing.

In answer to your question in part 8, I think your friend may have been more concerned about section 16, which follows on section 15, where it says that if the health care practitioner is still saying that the person is incapable and there has to be a board hearing, there are certain circumstances after 48 hours in which the health care professional can go ahead and give the treatment that was originally ordered by the substitute decision-maker. That may have been where the issue was, and that's why you need to talk about all those things, but it's kind of at a remove from just overruling a personal directive.

**Mr Parker:** I just want to help you out with one point that, if I understood you correctly, caused you some concern. In your capacity as an advocate, your concern is that you may not be entitled to be appointed as a substitute decision-maker, and I want to reassure you that that need not be a concern under the proposed bill, that you are fully entitled to be selected as a substitute decision-maker. There's no bar against you per se.

**Ms Berry:** But there would be in my capacity as a support worker providing services for compensation. Now I'm just wondering, is that the same?

**Mr Parker:** That the same concern is being addressed there, the issue of the control over the individual; that's the consideration that has to be balanced off. The point has been made, and I think it bears repeating, that the solution to all these concerns, of course, is for the individual to take out a power of attorney for personal care before the issue arises.

There will always be situations where an individual, for one reason or another, won't be comfortable with the laundry list of selections available under the statute. For their own particular reason, they will want somebody else to be chosen as their personal decision-maker, and they have that right under this legislation. Frankly, they have the right under the existing legislation also to designate anyone they choose by their own criteria. They don't have to have a family member, if they're not comfortable with a family member having that degree of influence over their life. The bill allows that flexibility. They're not bound to have a family member make their decisions for them if they would rather have a friend or a member of



the community or someone else of that sort. That flexibility is in the bill, and that's the solution, I would suggest, for most people who have the concern you're raising.

1400

**Mrs Caplan:** I'd like to pursue that a little further, and I'd like the ministry to give us some clarification to see if I'm correct about how it would work. There are several different notions here: First is the notion of attorney under the Power of Attorney Act, the second is guardian, and the third is the substitute decision-maker. It's my understanding that you or anyone could choose anyone they wish to be their attorney, and as long as the attorney does not witness the power of attorney, it is a valid power of attorney. So your friend could name you, even though you are a paid caregiver, under a power of attorney as the decision-maker when it was necessary to have a substitute.

Where you would have a difficulty is if there is no power of attorney. The question then is, are you in the hierarchy? The answer in this legislation is that it would permit a caregiver, but you're down the list on the hierarchy. A third question is, who can apply for guardianship? It's my understanding that anyone can apply for guardianship as long as they don't have a conflict. That's where I'd like some clarification, because I think these are the questions you wanted answered, correct? Let's see if we can get the ministry to go on the record and straighten that out.

**Ms Spinks:** Under the current legislation it works this way: for the power of attorney for property, you can name anyone you choose. As to a guardian for property that's appointed subsequently, after incapacity, usually because there is no power of attorney, at present a person who provides residential, social training, advocacy, or support services for compensation cannot be appointed by the court unless that person is also an immediate family member.

The same applies with respect to court-appointed guardians for personal care. However, unlike powers of attorney for property, there is a restriction in the current legislation on who can be named as attorney under a power of attorney for personal care. That extends to a person who provides residential, social training, support or advocacy services for compensation, unless that person's a relative.

The amendments will continue that restriction on powers of attorney for personal care. The rationale is that the level of capacity required to make a power of attorney for personal care, unlike a power of attorney for property, is extremely low. However, the change being made is that "advocacy services" are being removed from that excluded list for powers of attorney for personal care, mainly because of the repeal of the Advocacy Act. The term was included to address advocates who were in the business of doing advocacy for the commission; that was the original intention.

However, as you've heard from a number of preservers, if the court is looking at an issue and a judge is there to examine the merits of the case and impose terms and accountability on the person who's appointed, the judge can make a decision to appoint a service provider, but only a judge can do that.

**Mrs Caplan:** So your concerns are valid. The answer you've just had is that your concerns are valid under this legislation. If you want to make suggestions on proposed changes that would deal with the circumstance, feel free to do that, but it's important that the clarification we've had suggests that the situation you've identified would not be possible under this legislation.

**The Chair:** Thank you, Ms Berry. Your time is up. I think you've reinforced the need for education, with the confusion that surrounds not only this proposed act but the prior act. We'll be considering that.

JOCELYN HUCULAK

**The Chair:** Ms Huculak. Please proceed.

**Ms Jocelyn Huculak:** As you know, my name is Jocelyn Huculak. I'm a lawyer who practises in the community of Thunder Bay. Primarily my practice is in the area of wills and estates administration as well as powers of attorney. Because of the nature of my practice, I've had considerable exposure to areas concerning consent and capacity, and that's my reason for coming before the committee today.

I have taken the time to review Bill 19, and while there are probably a number of areas in Bill 19 I would like to address, I understand that time is short today so I intend to focus my comments on the proposed Health Care Consent Act and, in particular, I have three points I would like to raise or discuss with the committee with respect to that.

The first point I would like to bring to the committee's attention is one that I call objective versus subjective standards, and in particular, the part of the Health Care Consent Act I'm referring to is the definition of "treatment" you'll find under section 2 of that act.

It's probably an oversimplification but the whole point of this act, as well as the current act, the Consent to Treatment Act, is to provide a framework for obtaining consent to treatment. I understand that one of the present concerns with the definition of "treatment" under the existing legislation is that it may be too broad or it may not exclude situations where consent may not be necessary or where something may or may not properly be considered to be a treatment.

I note that in the new definition of "treatment" there has been an attempt to try and provide a little more guidance and a little more clarity as to what a treatment is or is not. In doing so, though, I think the definition that is proposed opens up a loophole. My particular concern is with clause (g) of that definition. The section basically provides what a treatment is and then it goes on to say that a treatment shall not or does not include "a treatment that in the circumstances poses little or no risk of harm to the person." My concern with that is the standard that would be used in deciding what poses little or no risk of harm and how that decision should be made.

It's my submission that the way that definition is written right now leaves it open to a great deal of interpretation and primarily leaves it open to a subjective interpretation by the health practitioner who would be asked to decide if a proposed treatment actually is not a treatment because it doesn't pose a significant risk of harm or poses little or no risk of harm.

I would advocate that section be tightened up so that rather than using a subjective basis for deciding what should not be a treatment, I would suggest or advocate that be determined on an objective basis, and the way I believe that should be determined is by asking that the standard be raised to what would be reasonable in the circumstances or, in other words, to add the word "reasonably" in there so that section would read, "a treatment that in the circumstances reasonably poses little or no risk of harm to the person."

I believe that by doing that we would tighten that section and require that not just in the health practitioner's opinion alone the treatment poses little or no risk of harm, but we would actually require that determination be made in the mind of a reasonable health practitioner. The point of doing that, I think, would be to provide a protection, so that in circumstances where there may be a tendency to call something or to decide that something is not a treatment because it's expedient, I believe we would impose a greater standard on the health practitioners.

If I could give a particular example, if we're dealing with perhaps an elderly patient and someone who is probably not capable of making their own treatment decisions, it's probably a lot easier to deal with, or administer treatment to that individual in certain circumstances if we decide that something is not a treatment, because then it means the health practitioner doesn't have to go through the exercise of determining capacity, and if there is no capacity then finding a substitute decision-maker.

#### 1410

If we tighten that section up and make it a little bit more difficult or impose a higher standard on deciding what should not be a treatment, then I believe there's less likelihood that section would be abused so that things that should properly be considered treatments are not considered treatments just simply because it's expedient to do so. That would be my suggestion with respect to that particular subsection.

The next section of the Health Care Consent Act I'd like to deal with is one I've entitled "Notice of Rights Upon Finding of Incapacity." I guess what I'm looking for here is a little bit more protection for the incapable person. At present under the Consent to Treatment Act, if a health practitioner finds that an individual is incapable with respect to treatment decisions, there is an obligation imposed on the health practitioner to not only inform the incapable person of the finding of incapacity, but also to inform that person that they have the right to have that finding reviewed and also to meet with a rights adviser if the person so indicates.

Under the proposed legislation, much of that is gone, so while the health practitioner still has the power to decide whether or not someone is capable or not capable, there is no requirement for communication to the incapable person that they have the right to have that finding challenged. It's my submission that taking that away or removing that obligation from the health practitioner to make that information available to the incapable person really provides them with a very hollow or a very limited right. Certainly their right to appeal does exist, and that

hasn't been taken away, but unless the individual is provided with some information or is given some notification of it, it may be a useless or a very hollow right that is not used.

It would be my submission that this section should be reworked so that the obligation is still imposed on the health practitioner. I don't believe it is asking too much of the health practitioner to pass that information along. I can't say whether or not that currently happens in all practical situations now, but if we go by the letter of the law, of course it should. I suggest that something similar to the existing legislation be continued in the Health Care Consent Act.

In addition, along with that, I have some concerns about the fact that under the present situation, when a finding of incapacity is made, there is a 48-hour waiting period that's imposed upon the health practitioner before treatment is administered, and the purpose of that 48-hour waiting period is obvious: obviously to allow the incapable person time to decide whether or not they wish to challenge the finding of incapacity.

With the new or the proposed legislation, it reads such that the health practitioner may go ahead and administer treatment as long as they don't know that the person intends to appeal the findings. I believe there's the possibility there that we may see situations where a person simply hasn't been given enough time to make their decision about whether or not they want to challenge the finding of incapacity, and yet because there was no mandatory waiting period or simply because they didn't know their patient intended to appeal, the treatment may already have been administered. In that sense, I think that clearly there would be a violation of the individual's right. Although the appeal could still go ahead, it would probably be quite useless if the treatment had already been administered.

In summary, my suggestion with respect to that point would be as well that some type of a mandatory waiting period be reinstituted along the lines of what currently exists in the Consent to Treatment Act.

The last section I'd like to address is one that I've entitled "Offence Provision for Health Practitioners." When I've talked with friends of mine who are health practitioners, this usually gets them excited.

Much of what we see in the existing legislation and also in the proposed legislation seems to be addressed at the substitute decision-maker. We tell the substitute decision-maker that if you don't make decisions in keeping with wishes that may have been set out or if you don't make decisions that are in keeping with statutorily prescribed principles, there are going to be penalties for you. We don't just leave the penalties as they may exist at the common law or the civil law, but it's been taken one step further with this legislation and the penalties have actually been included in the legislation. For example, if a substitute decision-maker makes a decision regarding treatment that goes against wishes that are known to that person, that person may subject themselves to a fairly stiff monetary fine in the event they are convicted of that breach.

While we've gone a long way I think to strengthen or to give weight to the fact that wishes and instructions



must be followed by substitute decision-makers, I'm not sure we've done the same with respect to health practitioners. An example of that would be wishes or a living will or an advanced health care directive that an individual may have made.

We've made it very clear to the substitute decision-maker, "Follow what's set out or there is a penalty prescribed by the legislation that will be applicable." We haven't said the same, though, to the health practitioner. Certainly, if a health practitioner was to go against known wishes, it doesn't mean there aren't civil remedies that would be available, but I think we would strengthen or perhaps bring home the importance of the individual's wishes to health practitioners if similar offence provisions were provided in this legislation directed at them.

Naturally, as I've said, there are civil remedies. An individual or their family may decide to pursue a civil remedy. They may decide to pursue a remedy that deals with the particular disciplinary board that regulates that profession. However, I'm not sure that's enough to help bring home the point to health practitioners that they are obligated to not substitute their own judgement, but to follow the wishes of their patient, regardless of whether or not that person is capable.

I would strongly suggest, along the lines of what has been imposed for substitute decision-makers, that similar offence provisions be included that would apply to health practitioners who breach their duties that are imposed by this legislation. Whether or not the offence provisions need to be as stiff as the monetary fines that are imposed, I'm not going to comment on, but I think there needs to be something more. If the point of this legislation is to make it easier for people to know that they can express their wishes and know they'll be followed, we need to impose the same requirements on both substitute decision-makers and health practitioners.

Those are the comments I wish to make with respect to this legislation. I'm open to questions now or comments, if there are any.

**Mr Ron Johnson:** Thank you very much for your presentation. It was very insightful. I want to ask a question with respect to your concern on the advice of rights. You specified that in every case the least the practitioner can do is advise of the rights. I want to know how you feel that can work, because even under the current legislation and the current Consent to Treatment Act, it doesn't impose a positive duty on a health care provider to advise of rights in every case. You can look, for example, that it doesn't apply when someone's under 14 or in an emergency situation or where there's not a controlled act. I want to get your feeling on when you feel it's imperative this happen.

**Ms Huculak:** I guess it wouldn't be too hard to take those parameters you've just set out and say that in those situations, except for those you've just set out, there is a positive duty to provide rights advice. I know that under the Mental Health Act, for example, rights advice is often provided, and I think something similar to the manner of delivery of rights advice under the Mental Health Act would work here.

I don't know that we still need to have the rights advisers, but we need to at least make some effort to communicate to people that they have the right to

challenge this finding of incapacity, and whether it's simply providing them with a form or reading a notice to them, something along that line so they are at least aware that if they want to challenge it, they do have that right. I know that under the Mental Health Act, the system they presently have seems to work very well, so it may be just a matter of importing that into this legislation.

**Mr Parker:** I want to pursue the same point because it's one that's on the minds of all of us on this committee, and the minister on day one indicated that he was open to suggestions on this point, so he's anxious to get some advice on it.

We're getting different points of view from different witnesses. Some are saying that it should be left to the discretion of the medical profession. Some have said that the way the news is broken to the individual should vary under the circumstances, that the practising physician should vary the message according to the circumstances and sometimes tell them point-blank and other times just sort of let them know, "Oh, by the way, somebody else is going to be making this decision; is that all right?" that sort of thing. Can you give us some guidance, your thoughts, on just how the legislation should address the point, how much detail it should have and have much should be left for regulation or for the professional bodies?

1420

**Ms Huculak:** It's not an easy question. I guess whether or not the information is passed on to the individual in some sort of a softened fashion, it still needs to be communicated a way that is appropriate to the situation and to the individual's background so that he clearly understands the nature of what is occurring to him. They need to understand they're being told that they cannot make this decision for themselves and that the health practitioner is going to look to someone else to make that decision.

I don't know that it would be appropriate in the legislation itself to set out in detail those circumstances. It may be that by regulation some guidelines could be proposed, but I think that it shouldn't be too difficult if we're going to decide on, for example, an age at which point this rights advice should occur if for example we're going to decide what types of treatments should fall under this. It may be just a matter of dealing with this idea of controlled acts and what should be excluded.

Because we're telling someone in this situation, "You can't make this decision for yourself," it's very serious. I don't know that we should provide something in the legislation that softens it. I think we should make it clear to the health practitioners that they are obliged to explain clearly to their patient that this is what they have found, and to make it clear they understand that they do have that right to appeal it or to question it.

**Mr Parker:** One of the concerns we've heard from the medical profession is that sometimes merely breaking that news is in itself counter to the clinical treatment that they're trying to administer to the patient and that it harms the patient. How do we reconcile that concern over the concern that you're articulating here?

**Ms Huculak:** It's a tough balancing act. I don't know, though, that merely informing someone that they're



incapable—I can see that it's going to perhaps delay the administration of treatment, but ultimately it shouldn't affect the overall course of the treatment. If the person's incapable, and whether or not an appeal goes ahead, ultimately the substitute decision-maker will make the decision to accept the treatment or not. So the end result should still be that the treatment hopefully, if it's accepted, wouldn't be delayed all that long. I guess there's no easy way. There's no easy way to tell somebody, "Look, you can't make this decision for yourself." But, given the consequences that it carries with it, I'm not sure that there should be an easy way to tell people that.

**Mr David Ramsay (Timiskaming):** I'd like to follow up on this point and maybe have a discussion with government members also. I am very concerned too about this omission in the bill and I'm pleased to hear from Mr Parker that the minister is looking for some advice.

The problem here seems to be as to the method of delivery of rights advice, though unfortunately the whole principle there is omitted from the bill. I strongly believe that the rights advice should be there and should be administered to the person who's been deemed to be incapable. Do you think then, if we put that in the bill, that maybe we could leave the delivery mechanism to the discretion of the professional but we do spell out that the person is notified of his right to appeal that decision, that finding?

**Ms Huculak:** At the very least, I think there should be some positive obligation to inform them of their rights under the circumstances. Whether delivery is to occur orally or in written form, it may be possible that you can leave that up to the discretion of the individual, but there should at least be that positive obligation.

In thinking along with that, though, obviously, if there's a written communication of the rights advice, it's a better way for us to know that the information was communicated. That may raise all kinds of problems of, "Does the individual understand the written communication that's given?" that type of thing too, but at the very least there should be that positive obligation to provide it.

**Mr Ramsay:** Mr Chair, could I address the question to Mr Parker about that? Do you think that would be an acceptable way of finding the middle ground on this, that we would put in the act that rights advice would have to be delivered but that the method of delivery could be left to the discretion of the health care practitioner?

**Mr Parker:** I would suggest that's one of the tasks before this committee. Maybe we'll have to give that some consideration when we get to clause-by-clause.

**Mr Ramsay:** So you're saying we are open to have that discussion?

**Mr Parker:** I'm saying that's what the minister said on the very first day, so certainly if it remains of interest to the committee, then we'll get to it.

**Mr Duncan:** Substantively, from your position—I recognize you're not here representing physicians and professionals—because you've put some very substantive arguments, do you see anything that would concern a practitioner about having a positive duty to inform of a right of appeal available to a person?

**Ms Huculak:** From my experience I know that practitioners don't like to be involved with doing that. A

lot of times they view their schedules as being under a great deal of stress and they may see this as the imposition of one more thing they have to do in an already overcrowded day.

None the less, because they are the ones being asked to make a determination of somebody's ability to make their own decision, I don't think it's asking too much of them to impose this duty on them. In doing so, it's probably going to take a great deal of education to help them understand the reason why they're being asked to do this and also to help them to provide the delivery of that service or of that rights advice to their patient.

**Mr Duncan:** Let me just ask you hypothetically—let's say the government imposes this positive duty, and then a practitioner fails to advise somebody of their right to appeal—what, potentially, could happen to that person. There would be a violation of the statute.

**Ms Huculak:** Beyond that, it's a violation of the statute. In addition, though, you may see that physicians or health care practitioners could put themselves in a situation where they're going to be subject to civil suit or perhaps disciplinary proceedings from their own governing board. I guess maybe this ties into where I talked earlier about the need to impose offence provisions for health practitioners as well, and perhaps this is one area where that would be imposed, but failure to provide the rights advice may lead to some particular offence that is specified right in the act.

**Mr Marchese:** Thank you, Ms Huculak, for your presentation. I want to agree with you on the whole point about notice of rights upon finding of incapacity. I should tell you that the majority of deputations agree with you, with the exception of people like the Ontario Medical Association.

**Ms Huculak:** Why does that not surprise me?

**Mr Marchese:** I wanted to get to the point soon that you made in the third recommendation as well.

Other than that group of people, the majority said rights notification is a right and an obligation on the part of health practitioners, and I agree. The medical association says that doctors are not lawyers, and I think they pointed out that this is almost a legal matter. What is your response to that kind of response?

**Ms Huculak:** We're not asking the doctors to explain to them what their rights are, how the appeal works and what the consequences of it may be. All we're asking of them is to tell their patient: "If you don't like what I'm telling you, you have the right to challenge this. If you choose to do so, hire a lawyer or go to legal aid; probably legal aid wouldn't fund this, but you have certain legal rights in this case. If you wish to pursue them, you should go contact your lawyer." So we're not asking them to interpret their rights or to provide them with advice; just to tell them that they exist.

**Mr Marchese:** I agree. My colleague and I were talking about this, and a number of people were saying that to give rights advice could harm the patient. We were just saying to each other that not to give information to the patient could be harmful to the patient. Would you agree with that?

**Ms Huculak:** Yes, I would agree with that.

**Mr Marchese:** On your third point, about offence provisions for health practitioners, I think it's a reason-



able thing to do. The medical profession says that what we had in our current bill was very adversarial. I would presume that if we included such a thing as making it an offence with a liability for monetary fine upon conviction for breach of duty under the HCCA by a health practitioner, they would similarly think that this is of course controversial, adversarial, doesn't trust the practitioners and so on. But I think if we apply those standards to substitute decision-making people, why couldn't we do that with health practitioners? I think it's reasonable.

**Ms Huculak:** Yes, I agree with that.

1430

**Mrs Boyd:** On your first point about treatment and defining treatment under clause (g), I agree with you that the reasonable prospect is probably the thing we ought to put in there, because we all know, and as in fact the OMA admitted this morning, in almost any treatment something can go wrong and they need protection as well in terms of that.

I have a different concern about this, though, because there isn't a clear definition of what is treatment and what is called "personal care plan" in here, or "daily activities," which I think is what people want. One of the issues has been around nutrition and hydration for people. What goes on all depends on what side of the fence you sit on. But there are other issues around treatment that really call out for a bit more definition. Would you agree that we need at least some kind of schedules or something attached to this that give us a much better idea about what is treatment according to the act, what is a daily activity and where there might be a crossover?

**Ms Huculak:** I think that would be helpful. Also, I think it would be helpful because we're asking the health practitioner who proposes the treatment to determine if it is a treatment or not. While in most cases we may be dealing with physicians, we may not be dealing with physicians; they may be people who are coming to it with a different perspective or from a different educational background, so it would probably be useful to have something that is more explicit to everyone who is being asked to make this determination.

**Mrs Boyd:** Yes, because it's almost a truism that in some cases, where people are close to the end of life, they cease to be offered food. That really becomes a bit of a problem in terms of where that crosses the line into withholding the necessities of life.

**Ms Huculak:** Yes.

**The Chair:** Ms Huculak, thank you very much for attending. It indicated a lot of interest from the committee members. I commend you on your presentation.

#### PEOPLE ADVOCATING FOR CHANGE THROUGH EMPOWERMENT

**The Chair:** People Advocating for Change Through Empowerment. Mr Len Maki, I understand you're accompanied by Ms McKnight. I thank you for your patience in waiting to be heard. You have half an hour, including questions. Please proceed.

**Mr Len Maki:** I thank you for this opportunity. I was very interested to hear the discussion that took place beforehand. I'm getting a better sense of why so many

people who choose a career in politics are themselves lawyers.

**Mr Marchese:** Some of them.

**Mr Maki:** Some of them; not all of them.

I am presenting on behalf of People Advocating for Change Through Empowerment, PACE, for short. PACE is a membership-driven, psychiatric consumer-survivor group. Our definition of a consumer-survivor is an individual who has been hospitalized and/or has used mental health services for psychiatric reasons or has been diagnosed with a psychiatric disability.

PACE welcomes the opportunity to speak to this committee and to this government in regard to Bill 19. We hope this is a sign that the government will have a meaningful dialogue with community groups such as PACE and hope that our comments will be treated with due notice and respect. This comment is made not out of disrespect for the members present, but because one of the ongoing concerns that people with psychiatric disabilities have is a general lack of understanding and respect from members of the public. Inherent in this is also an historic lack of consultation with such individuals and lack of opportunity for involvement in the decision-making process.

Bill 19, an act to amend the Substitute Decisions Act, repeals the Advocacy Act and Consent to Treatment Act and introduces the Health Care Consent Act. In this presentation I will refer to the above as Bill 19. Because so many of the amendments are interconnected, I find it difficult to speak about them in discrete sections. We have no lawyers on the staff at PACE to read this lengthy and complicated legislation. What follows is a presentation based upon the views of the membership of PACE, many of whom have ongoing need of institutional health care facilities, have at times the need to appoint substitute decision-makers or have them appointed for them. Many of the members also face systemic factors, including lack of education opportunities, and therefore have a hard time understanding the significant consequences and ramifications of appointing decision-makers or having knowledge available to them concerning their basic rights, including the right to appeal certain decisions.

The issues relating to advocacy and rights advice are of particular concern to us. We feel that an independent rights adviser or advocate is the only way to truly ensure that objective advice is given. This is not to take away from the well-meant intentions of family members, many of whom are extremely effective and have had to deal with family members' problems or issues for far longer than anyone else. We value their contributions, but it should be remembered that being a member of a family in no way guarantees objectivity or following the wishes of that individual.

One may compare the personal care and treatment wishes with a person's religion. How many of you know of a person who has either renounced their family of origin's faith or has converted to another faith altogether? Their family goes along with this to humour the individual, but in a time of crisis or fatality the family will often conduct religious services within the faith base of their choice, knowing what is best for the person, rationalizing their actions with such thoughts as, "He didn't really

meant that. It was only a phase," or, "What he really meant was this." Of course, from their point of view they are right, they are the family, they know best. The individual's wishes, however, are ignored, left aside, given no validity. Historically, people with psychiatric disabilities have had their desires and wishes ignored and left aside.

Individuals' wishes regarding treatment and disbursement of personal property are analogous to religious convictions, with the underlying fact remaining that it should be left to the individuals to decide for themselves as much as possible. Objective third-party advocacy is one of the ways in which to remedy this situation and ensure the individual's wishes towards treatment and personal care are kept in mind. We feel there is a need to have this formal mechanism in place.

I don't know if any of you have ever known someone with a psychiatric disability or if you have ever suffered from any yourself. The concept brings fear and anxiety to many people's minds. It is an image of a psychological nightmare, the image of the lunatic wrapped in a strait-jacket which is pervasive in movies, literature and television. It is an historical image which groups like PACE work hard towards dispelling, yet the image remains. It is an image that people do not want to be associated with, for people do not want to lose control. In short, no one wants to be crazy.

The facts, unfortunately, are that people do suffer from psychiatric problems of varying degrees. How this society deals with them in terms of treatment and in terms of basic human rights, including the right to information, is one of the equations which governments and their policymakers must deal with. It is hoped that this is done with compassion and fairness, keeping each citizen's rights in mind.

I would like to ask the indulgence of the members of this committee for a brief time. I would ask that they try to imagine what it must be like to live with a disability, in this instance a psychiatric disability. You may be aware that your disability is going into an active cycle, meaning that you need some form of treatment, and you have taken the appropriate steps to secure treatment. Imagine that treatment decisions begin to be made for you. This is because someone has made an assessment of incapability. You are not informed of this, nor are you given any reason why things are being done to your person, things which are intrusive and to which you personally object.

If you value having control over life, as most human beings do, you may wonder why such things are happening and also wonder why they are happening without your consent or knowledge. It could make one feel hijacked by the health care system. It could also make them think that they are more profoundly sick than diagnosed, for no one has ever asked them any questions regarding permission and no one has told them that a substitute decision-maker has been given legal authority to sanction treatment decisions on their behalf.

No rights advice has been allowed for. Above and beyond the disabling symptoms of your disability, which may leave one in a state of confusion, this is possibly compounded by the side effects of psychotropic drugs

used in an effort to treat your illness. Consequently, you have no idea why things are happening or why all your decisions are being made by other people without you knowing it. This scenario is what could happen to a person upon admission under the amendments made through Bill 19.

#### 1440

The concept of suffering from a psychiatric disability or illness is a frightening concept to most anyone. People do not envy the idea of being at a loss of control of their mental functions or having their thought processes in a state of confusion. Having information regarding decisions being made and rights available to you can and, we feel, does help relieve some of the anxiety associated with being admitted for treatment—not only for individuals with psychiatric disorders but for any kind of illness.

Just as people have wanted the opportunity to have input on this and other bills this government is enacting, people want and need input and information on all important decisions affecting their lives. In a democratic country such as Canada, one expects such things. People feel disempowered when this opportunity is taken away. When people with psychiatric disabilities feel disempowered, one of the results could very well be despondency and a lack of cooperation with health care providers.

When people feel a sense of control, they respond better to their environment. It could be argued that people could respond less favourably to treatment if they fall into a pattern of despondency, feeling out of touch, disrespected, treated as unimportant. A general feeling of self-worth is necessary in all human beings. This necessary self-worth is undermined by policy decisions which disregard the rights of all people, including those with disabilities of all kinds. It makes people feel worthless, unwanted, uncared for by specific people around them and by society in general.

Fear is one of the biggest issues facing individuals with psychiatric disabilities. Fear of society, fear of specific people around them, fear of their own illness all play into this web of mistrust. People have to work very hard to overcome this disabling emotional state. Providing information to people is one way of easing the fear around treatment and consent issues. When people fear something, they have a natural tendency to avoid it. If there are further reasons to fear an assessment of incapacity, fuelled by the fact that a substitute decision-maker can decide things for you without even the basic dignity of being informed when this happens, it could result in people avoiding going for an assessment even if they know they are getting sick.

If this government wants its citizens to participate, then it must allow them access to information, including information about treatment, and also allow them the basic dignity of informing them when it has been deemed that they are no longer able to make their own decisions. Some form of rights advice is what we would like to see. Discussion on what form of rights advice is available within a cost-effective scheme is a question which the members of PACE would be very interested in being a part of.

There is a concern regarding the story in the February 9 edition of the *Toronto Star* which, although it does not



speak directly about this bill, does relate to the availability of legal services, possibly including rights advice. This is the issue of cutting funding to Ontario's community legal clinics. We believe this would be a mistake and in fact we would endorse the expanded funding of their operations as a possible solution to the issue of how to ensure that rights advice is continually available to vulnerable people, including people with disabilities of all kinds.

It is because we live in a democratic province that these hearings are taking place, and it is because this government is willing to listen and make changes that are necessary for the inherent rights of the person to be recognized and enshrined as a part of the amendments to this bill. This government was elected in a democratic process. As a part of that process, it informed the general public of its views and concerns. The public made an informed choice. What we are asking for is the same thing. We want the ability to make informed choices about treatment and to be informed and advised on a continuing basis when it has been deemed necessary to have others make those choices for us.

There are other specific concerns about the changes that need to be addressed as well.

I would like to ask the members present if they would envy anyone who received a jolt from a cattle prod. I am sure that if you were in a hospital or another type of treatment facility and a health care provider zapped you with a cattle prod or you received some other form of electrical shock as part of treatment, you would question the appropriateness of such pervasive and extreme tactics. Anyone who has accidentally given themselves a shock from a frayed electrical cord knows the sensation of voltage running up your arm. Imagine this as a form of therapy. Imagine that people providing care to you were under no obligation to justify this. This is one of the potential outcomes from the amendments found within Bill 19, specifically subsection 43(5). While we do not feel it is the intent of this government to allow willy-nilly use of such things, we hope you will consider putting legislative safeguards restricting the use of such techniques to only those circumstances where it is absolutely necessary.

We are concerned that consent to treatment in one facility can be transferred to another facility. We believe this should be limited in its application.

We believe that a statement of relationship to the person still be required to be signed by a family member acting as a substitute decision-maker.

We believe it is a mistake to allow health care providers to become guardians for vulnerable people. This has the potential for serious conflict of interest.

One of the positive changes we see is the move to standardize capacity assessments and to control the cost of these assessments.

Overall, we would encourage the committee to review the decision to totally repeal the Advocacy Act, believing that some form of rights advice is essential for people with disabilities in a democratic and just society. We understand the need to be cost-effective in this procedure but hope that this government does not simply throw away all the hard work, time and money already spent by

dedicated bureaucrats, community representatives and volunteers, including people from consumer groups like PACE, in establishing the Advocacy Act. We hope that a middle ground can be reached between the government of the day, professional and family groups, many of whom are opposed to the Advocacy Act, and groups like ourselves.

In the final analysis, we all want much of the same thing; we want productive, healthy communities with their citizens acting in a responsible and inclusive manner. Rights of the individual are one of the flagstones of a democratic society. Advocacy is a way of ensuring that the rights of all citizens are heard and respected. It is a way of making sure that people understand the laws under which they are governed, thereby allowing the democratic process to take place.

**The Vice-Chair (Mr Ron Johnson):** Thank you, Mr Maki, for your presentation. We're going to entertain questions now.

**Mrs Caplan:** Thank you for a very thoughtful presentation. I'm going to address a couple of the things that you've stated. I thought you made the case extremely well for individuals having the right to be informed and how they react and how people react when they feel powerless and hopeless and helpless. I think that's very instructive and I hope the government is listening, because right now—and we've heard this from actually a psychiatrist who made a presentation before the committee; he was from Hamilton—it's standard procedure, and it has been for many years, that individuals in a psychiatric facility who are deemed incompetent under the Mental Health Act are told. They engage in a conversation and it hasn't adversely affected their health. While it's difficult, it's an important part of their therapy and wellbeing.

So I think you make the point extremely well, and while there may be other providers who are not used to engaging in those kinds of conversations, and granted it is difficult, I think the government shouldn't fear requiring that obligation from all providers who will have that power, especially given the fact they didn't mention it, but this legislation, section 27, on page 78 of the Health Care Consent Act, frees providers from any liability for any treatment given if they believe it is in good faith. I don't have an objection to that, provided that the other side is the obligation that people be informed and know their rights and be assisted in an appeal, if that's their request. I thought you'd make that point, because you've made it extremely well in your presentation.

1450

The other concern I have, and you raised it, has to do with faradaic therapy, the use of electroshock. I don't think people realize—I'm not even sure the government members realize that what they've done in the legislation would allow that therapy outside of a Comsoc facility if any professional deemed it to be a treatment, under the consent act.

While we do have in place standards and protections in the Comsoc facilities, this opens the door to a professional, a psychologist, for example, providing the treatment in his or her office. You might say and I might say that no reasonable person would do that, but there

would be no penalty or sanction under this law if they did that. If you don't believe me, check with the lawyers. That's why I believe very strongly that while it's a treatment of last resort and I don't believe in an absolute ban, I do think there are very few cases, particularly the one we heard of the young man who inflicts serious damage on himself—

**The Vice-Chair:** I'm sorry, we're going to have to move on.

**Mrs Caplan:** I thank you for your presentation. I hope the government has heard you. I don't have any questions of you. I think you've been very clear.

**Mr Marchese:** Thank you, Mr Maki, for your presentation. Most of the delegations that have appeared before us in Toronto and here and I'm sure everywhere else have agreed that some sort of advocacy needs to go on and it should be done as part of an obligation of government, and that rights advice is critical and important. Other than the Ontario Medical Association, most people have agreed.

It would seem to me absurd that the government or most of these members would not do something with respect to changes or amendments to this bill, having heard most people say we need something. What most of you are proposing is that if you're going to get rid of advocacy and the commission altogether, then there be some middle ground, whatever that middle ground is. Some of the people talked about having legal clinics provide that. I'm not convinced that is the best route, given that they're losing a great deal of financial support; understaffed as they are, I'm not sure that's the best place to provide it. But the government has a duty to be able to provide what was in the previous government in some form, so I hope they're hearing you.

Another thing that many other people have spoken to is that many believe the statement of relationship to the person should still be required to be signed by a family member, as the way it existed. What it does, as some other people have said, is to trigger the sense of duty and obligation on the part of the other person in terms of what he or she is assuming. So you're not the first, you're one of many saying, "Retain that statement of relationship."

**Mr Maki:** I'm glad to hear that.

**Mr Marchese:** On the conflict-of-interest issue, that too is something that most people have raised with respect to caregivers, so you're not the first.

On the whole issue of electric shock, many have spoken about that as well. The reason it's important for us is that it's people like you who have this experience and have worked with people who have these experiences, and if we don't listen to you, who should we be listening to? We're happy that you're making these interventions, because we are or should be informed by your experiences.

**The Vice-Chair:** Your party has a minute left, if you want another quick question.

**Mrs Caplan:** Ask if they were consulted.

**Mrs Boyd:** We don't need to ask if you were consulted, because you weren't, were you?

I too want to thank you for being very frank and for giving us a vision from the eyes of the people with whom you work all the time. That is very helpful.

On the faradaic stimulation issue, Mrs Caplan is quite right: Taking this away means it could happen anywhere. Quite frankly, having been responsible for stopping this in the particular facilities, there was always an urge to expand it, not to restrict it, because it is a way of controlling behaviour that appears to work very quickly.

When we look at some of the psychiatric treatments like initiating sexual experiences in order to get people over phobias and using electric shock therapy to control behaviours, using some of the other methods of ego destruction that have been used in psychiatry over the years, we know there are so-called treatments that may look as though they work to make people compliant but in fact are very destructive. I'm very glad you've made the statements that you've made.

**Mr Maki:** I would be very interested when and if the government has any sort of user-friendly guidelines when this legislation is in its final form. I would certainly encourage that so people such as our membership could have something clear to read and understand the total package involved.

**Mr Clement:** Thank you very much for being part of our process here. In fact, to perhaps recharacterize the record a bit, we on the government side consider this an integral part of our consultation. Rather than hold consultations behind closed doors with certain designated persons, we're having a public consultation. I want to thank you for being part of it, and please consider yourself part of the consultation, because we're listening very, very closely to what you have to say.

I just want to touch upon a couple of points. First, with respect to your submissions on electric shock treatments, faradaic stimulation, I want to thank you very much for your comments on that. It's certainly an area that has a lot of emotion and something we want to get right.

Typically, legislation of this sort can be permissive and then the government has the ability through consultation to be more restrictive once the general rule is in place in the legislation. So it may in fact be the case that we will be in a position to restrict that sort of treatment to specific facilities, like Comsoc facilities, or restricted to certain types of individuals in the treatment and care field. We would love to have more of your views on that. The minister has the power to regulate once the general rule is in place and you can start restricting it to specific circumstances, and we may be taking that into consideration.

With respect to your very forceful points on advocacy and rights advice, I couldn't agree with you more that it's an essential component of a free and democratic society. In fact, I would say it's a moral component. It's what makes us humans and full of morality, to have that moral duty there.

From your perspective, is it possible to have that moral duty more in terms of friends and family, with perhaps the government there to ensure that there's some training, some education, some backup, but that the intent is that it should be more in the framework of private individuals helping other private individuals? Is that not a way to construct this?

**Mr Maki:** As the individual representing the AIDS committee pointed out, I certainly encourage the concept of friends acting on that behalf, but once you get into



family members, you can't always guarantee that the person is going to act in an objective fashion.

**Mr Clement:** Quite right, and you can't always guarantee that a government-sponsored or -hired person would act in the same way either. Really, we're all individuals and none of us corners the market on being correct 100% of the time.

I come back to this. As an MPP, all of us around the table, every time we're in our community or constituency offices, we have a long train of people who come in and say, "I thought this government was here to help me, but person X in bureau Y has done this to me and it's totally unjust." I get a bit sceptical when someone says, "I'm from the government and I'm here to help." It doesn't always work out that way. That's why I want to keep injecting in there the friends and the family. They're the ones who love the person or who know about the person's treatment. If there are exceptions to that, which there always are, let's deal with those exceptions, but let's not make the blanket rule. Is that an unfair characterization?

**Mr Maki:** I agree that one has to be careful, and I'd return to the point I made that family members cannot always be guaranteed to be that objective individual. In essence, what you're saying is that neither can the government, and that's an interesting point. I don't quite know how to respond to that.

**Mr Clement:** That's fair. Maybe we could work together to figure this out.

**The Vice-Chair:** I want to thank both of you for your presentation. It was certainly appreciated.

1500

#### BARBARA ECCLES

**The Vice-Chair:** Our final submission of the day will be from Barbara Eccles. Good afternoon. You have 30 minutes for your presentation, and you may want to leave some time at the end for some questions.

**Ms Barbara Eccles:** If I'm lucky there will be lots of time at the end for questions.

I'd like to start by telling you a little about my background, for what it's worth. I was called to the Ontario bar on Wednesday—

**Mrs Caplan:** Congratulations.

**Ms Eccles:** Thank you. I'm not looking for laurels here, but—

**Mr Klees:** You're looking for a job, right?

**Ms Eccles:** That's right. I've been a lawyer for five days, but all through law school I've had an interest in the proposed changes to the health care legislation, the Consent to Treatment Act, the Advocacy Act and the Substitute Decisions Act. I studied what was then proposed legislation when I was in law school. Now that Bill 19 has come out, I had a look through that and had an interest in that, and since I don't have to write law school papers any more, I thought I'd write something for you people.

I prepared a short, five-page submission which basically outlines some suggestions I have for mostly nitty-gritty changes to the legislation, changes to bits of the wording to try to make it what in my opinion would be a bit more workable.

I'd like to start by saying there's a particular section of the Health Care Consent Act which is a very good change to see, and that's in section 16. Under the Consent to Treatment Act, I understand it used to be that if there were a finding of incapacity, the health practitioner would have to wait until an appeal period had run out before they could treat. I see that's been removed under section 16 of the HCCA, which I see as a positive change, because it will hopefully make the provision of health care a lot more efficient. Beds won't be sitting full while the health practitioners cannot treat. I think that's a positive change.

I've only set out five points in my submission. There is a lot of other things, but I know many people are talking about the removal of the rights advice, so I won't get into those issues.

I'd like to talk about five sections. First of all, section 18(1)5. That's the section regarding the hierarchy of substitute decision-makers under the Consent to Treatment Act, particularly paragraph 5, dealing with custodial versus access parents. I'll talk about that first.

Then I'd like to get into section 35.1, the proposed new section of the Substitute Decisions Act regarding the guardian of property and their treatment of property when the incapable person has written a will.

The third item I'd like to discuss is the role of the Consent and Capacity Board, the new name of the board under the new legislation, and I'd like to submit that the role of this board may be expanded to give them more things to keep them busy.

The fourth point I'd like to talk about is section 23 of the HCCA regarding emergency treatment, specifically the provision of emergency treatment to apparently capable people.

The last point I'd like to talk about is the three sections of the HCCA regarding when a health practitioner believes a substitute decision-maker has not acted in accordance with the act.

Getting right into it—or should I wait till the phone stops—

**Mrs Caplan:** Just ignore the phone.

**Mrs Boyd:** It's not for you.

**Ms Eccles:** I hope not. They can take a message.

I've set out the legislation in my paper. Page 1 is paragraph 18(1)5 of the Health Care Consent Act, which is on page 73 of the bill. It says that the parents of an incapable child—it must be, since it's a parent—can consent to or refuse treatment on the child's behalf. However, it says, "this paragraph does not include a parent who has only a right of access." Paragraph 6 goes on to say that a parent of an incapable person who only has a right of access can also give consent, so the way the scheme seems to be that the custodial parent has priority over the access parent, regardless of what any separation agreement may say.

In the interests of the right, hopefully, of people to order their own lives, it might be nice to change this section somewhat so the parents are allowed to change the order in a separation agreement so that if, say, the access parent has the child on the weekends and the custodial parent has the child during the weekdays, the access parent, if the parents so desire, will be able to

make decisions on the child's behalf when the access parent has the children.

The suggested revision I've set out on page 2 of my paper is just to add a line in paragraphs 5 and 6 saying, "unless otherwise provided by court order or written separation agreement." This allows the parties to organize their lives in a way that's a little different from the strict thing set out in the legislation. That's the first point. I'm just going to highlight them rather quickly so we leave time for you to ask me questions that I can't answer.

Moving on to section 35.1 of the Substitute Decisions Act, the proposed section set out at section 22 of Bill 19, it deals with the duties of the guardian of property, if there is a guardian of property in place. It states, "A guardian of property shall not dispose of property that the guardian knows is subject to a specific testamentary gift in the incapable person's will." There are three points I'd like to make here. The first one is that the definition of "specific testamentary gift" is not necessarily very clear, and to avoid a plethora of litigation and more money in lawyers' pockets, it might be nice to hone the definition of "specific testamentary gift" a little so we know whether that means a specific gift of property. Does the piece of property have to be mentioned in the will? Or if there's a residual clause in the will giving anything left over to little Joey, it doesn't look like that should be included in the definition of "specific testamentary gift," but it's not quite clear. It just leaves a little bit of uncertainty in the legislation.

The other interpretation of that, we were thinking, is that it could mean a gift to a specific person. I've set out an example in my paper on the bottom of page 2, "My CD collection to my nieces and nephews." Is that a specific testamentary gift, or is the guardian allowed to liquidate the CD collection in order to pay the bills? It's not quite clear, and it might be nice if there was a definition of "specific testamentary gift" offered. I haven't gone as far as drafting one, because I didn't know how we could draft it. This is just a suggestion for the committee.

A little bit more substantial, it says that if a guardian of property knows there's a will, the guardian of property can't dispose of the property unless they meet the other provisions of the section. I would like to suggest that the legislation be amended to make this a more positive duty on the guardian of property to find out if there is a will, because it's sort of an empty protection if the guardian of property has no duty to look and see if there is a will. This may be accomplished through fiduciary duties of guardians and that kind of stuff but it might be clearer if it's made—

*Interruption.*

Am I over?

**Mr Clement:** You are being defeated by technology.  
1510

**Ms Eccles:** Yes. It might be a little bit more clear and easier to interpret if it was set out in there, so I have a proposed amendment on the top of page 3 of my paper. The words are added: "A guardian of property shall not dispose of property that the guardian knows or ought reasonably to have known is subject to a specific testamentary gift." That will accomplish, I hope, that goal of

putting a little bit more duty on the guardian to be careful.

I'm not going to talk about the third point that I've put in my paper. You can read that. It's not really clear in my head—well, I'll bring it up. If you look at subsections 35.1(1) and (2), the effect of these two subsections together could be an unequal division of property to the beneficiaries. The example I'm thinking of is if a parent, in their will, leaves their house to one child and all the money to another child, under this section the guardian of property can get rid of all the money in order to fulfil his duties, and it seems like they have to do that before liquidating the property and selling the property off to pay for the bills and the other duties that the guardian of property has to fulfil. The result of this could be an unequal division of property in this circumstance where the testator has drafted their will in that way. I just wanted to bring this up to the committee that if this was the intended result of this section, then that's good, but if it wasn't, the committee may want to revisit that particular section.

The third thing I'd like to discuss is the role of the Consent and Capacity Review Board now, and the name will be the Consent and Capacity Board under the new legislation. As the committee may be aware, there's a general move in society towards giving more responsibility to administrative tribunals and that's what has been done in this case by creating a Consent and Capacity Review Board. The Consent and Capacity Review Board is assumed to have specific expertise or to develop the expertise throughout their decision-making process, in assessing incapacity and other aspects that they have to deal with.

It might be nice, in order to utilize this expertise, to transfer more decision-making powers to the Consent and Capacity Board and away from the courts. I've listed a few on page 3, the last paragraph of my paper, mostly decisions which are made by the courts under the existing Substitute Decisions Act and also under the proposed Substitute Decisions Act, things like appeal of the refusal of the public guardian and trustee to issue a certificate for statutory guardianship or an application to appoint a guardian of property or a guardian of personal care.

These decisions may be more appropriately made by the Consent and Capacity Board instead of the courts. This will have a couple of benefits such as I've already mentioned, utilizing the expertise of the Consent and Capacity Board; also reducing costs of applications to be appointed guardian, which can get rather expensive if you have to go to court with an application.

My fourth point: I'd like to draw the committee's attention to section 23 of the HCCA, and specifically clause 23(3)(e). This section deals with the ability of a health practitioner to administer mostly emergency treatment to an apparently capable person if there is some barrier to getting consent such as a language barrier. The health practitioner, according to subsection (3), is able to administer the emergency treatment if they satisfy the five criteria listed in subsection (3), and I'd like to focus specifically on clause (e), which states that the health practitioner may treat if there is no reason to believe that the person does not want the treatment.



In my submission, this is a bit too strict of a test to put on the health practitioner and may result in people not receiving emergency treatment who would not have refused the treatment. The example I have in mind is if there's a person with a language barrier who is a capable person but can't understand what's going on because they can't understand the language, and somebody tries to stick a needle in their arm and they flail around and push them out of the way. Is this a reason to believe that the person is refusing the treatment? I'm not sure. You would think that a court would say it wasn't, but it may put a doubt in the health practitioner's mind.

I just would suggest a revision, on page 5 of my paper: instead of saying "there is no reason to believe that the person does not want the treatment," to change it to "it is reasonable to believe that the person does not wish to refuse the treatment." This allows a health practitioner to still treat, even if there's just an inkling of a doubt that the person pushes the needle out of the way. That might be a nice revision.

The last point I'd like to bring up: I'll just draw the committee's attention to subsection 35(1) of the Health Care Consent Act, also section 52 and section 67, which contain very similar provisions. This one states that if consent to treatment is given or refused by a substitute decision-maker and the health practitioner is of the opinion that the substitute decision-maker did not follow the steps that they're supposed to follow in coming to their decision, then the substitute decision-maker may apply to the Consent and Capacity Board for whatever: to appeal, to have the substitute decision-maker removed or to have a different decision made.

It's my submission here that again the test is a little bit too lax. Just to backtrack a little bit, under the common law, as I'm sure you all know, health practitioners have a fiduciary duty to their patients to not kill them, to treat them properly and make sure that they get better. Are there any doctors here? I hope I have that right. That's not legal advice, mind you.

They're under a fiduciary duty, common law, that's outside of this statute. Subsection 35(1) and sections 52 and 67 give the health practitioner a discretion. They say they may apply to the board if they think the substitute decision-maker has done something fishy. It may be that this section, when you put it together with the common law fiduciary duty, imposes a higher standard on the doctor or the health practitioner to apply to the board if they think there's something fishy going on.

In light of that—and the law's not there, because the act isn't in place yet; we don't have any court decisions on it—it may be apropos to change the test and make it more of an objective test instead of a subjective test. Instead of saying, if the doctor is of the opinion that the substitute decision-maker blah, blah, blah, you may want to say it's reasonable, if the doctor is of the opinion on some reasonable basis that the substitute decision-maker did not follow. That might make the sections a little bit more workable from the health practitioner's point of view.

Those are my submissions. If there are any questions, I'll see if I can answer them.

**Mrs Boyd:** You may have only been a lawyer for five days, but I can tell you I've had many briefings from lawyers. This was very succinct and clear.

On your first point, I think I would agree with the suggestion you're making. Custody and access issues are tough enough and the kinds of disputes that occur are tough enough, and very often those disputes are around such things as making decisions about a child's health care; not so much where the child lives but those decisions around that kind of thing.

Your addition of "unless otherwise provided by court order or written separation agreement" I think is an excellent one because that would give more freedom, particularly in these days when we're trying to get people to fashion these agreements without going to court and to do it in an alternative manner. I think it might be helpful.

I can think of many cases where children, for example, spend 10 months of the year with one parent in one province and two months in another province with another parent. If the non-custodial parent happens to be in Ontario and that child is here, we'd really like that parent to be able to give consent to treatment while that child is here. I think that's a very reasonable kind of a situation.

1520

On your disposal of property, I suspect that the disposal of a testamentary gift was probably largely to try and protect property like a family farm or a specific piece of jewellery or a painting or something like that. I think you're right that it may well lead to an unequal division, not so much on insurance, because of course unless you name the estate the beneficiary, that wouldn't be a problem because you'd be naming a person. But certainly people sometimes leave their investment funds to one child and property to another, and you're right that it could end up being unequal.

I suspect that's a real challenge for the bar association and the law society in terms of making sure that lawyers, in helping people make wills, understand that's the situation, and in reviewing wills. I'm not sure there's any other way, but putting in "ought reasonably to have known" is probably a good protection in terms of knowing whether or not a will occurred.

On the role of the Consent and Capacity Board, I would agree that one of the big challenges with this kind of an act is the educational role, and particularly the educational role with health professionals, who have tended to be a bit resistant around a lot of this. I would certainly concur with you that a good use of those experts might well be in that way and in conjunction with the various colleges involved.

On emergency treatment, I don't know. I understand what you're saying, but it's a little bit difficult to think that it's really necessary in a lot of cases.

I do agree, though, in (e) with your opinion on the substitute decision-maker. There ought to be some reasonable basis for this belief. If you have a physician who will never, ever agree to a do-no-resuscitate order or to a palliative care order, and a substitute decision-maker who knows clearly that that's the wish of the person, you may get into this without a reasonable belief that they're actually contravening the act. They're just not doing what

the physician wants to do. So I think you've got a good point there.

**The Vice-Chair:** Thank you, Mrs Boyd. We're going to move to the government side now. I've got Klees, Clement and Parker with only about four minutes, so you have to juggle the time.

**Mr Klees:** We'll just talk fast. Congratulations to you on being called to the bar. You've done a great job here today.

I'd like to quickly address your first point with regard to the access parent. I think, for clarification, I'd like to draw your attention to subsection 18(4), which was really intended I think to address the issue you're concerned about. It indicates that despite subsection (3), which is the section you're dealing with, anyone else will in fact have the authority to give consent.

You're dealing with a situation here where you might have an access parent and a custodial parent where there isn't contention between the two. Certainly, if the access parent shows up at the hospital with the child, that access parent, under the terms of this legislation, has the right to make that substitute decision. We'll certainly look at your proposed wording, but I think what you're trying to do has been caught in this subsection (4). Maybe you can have another look at it as well and comment to us.

**Ms Eccles:** I've thought about that too. Your assumption is that there is no contention between the two. If it is a contentious situation, which it is in many divorce and separations, that's where the problem would come in.

**Mr Klees:** Actually, with regard to that, that's one of the reasons it is worded as it is here in terms of priority, because what we're trying to do is avoid an extended conflict between two parents. If there is a person who has custody, then if there is an agreement between the two, let's make sure that one parent has the right to make the decision so the treatment can proceed. It's a very complex issue, but we want to do what's right for the child here.

**Mr Clement:** On clause 23(3)(e), which you were discussing on pages 4 and 5 of your brief, just a quick point: In clause (e) in Bill 19 there's a double negative, and I notice that yours is not a double negative. I thought maybe the double negative would give us a little bit of latitude for the practitioner, but I'm wondering whether it's possible that yours is more restrictive than a double negative.

**Ms Eccles:** Certainly. It's certainly possible. Double negatives are always quite confusing in legislation to anybody but somebody who deals with this all the time.

**Mr Clement:** Do I go either way on this one?

**Ms Eccles:** I think mine is less because it's putting a reasonableness in instead of an absolute. Clause (e) seems more of an absolute.

**Mr Clement:** Okay. I was just thinking if all you needed was one scintilla of evidence that they didn't want the treatment and that test would be made, whereas here he's got to reasonably try to figure out one way or the other.

**Ms Eccles:** I guess here I'm looking at if from the doctor's point of view and the provision of treatment, with the assumption that the provision of treatment is good. The amendment was suggested so that more emergency treatment could be—

**The Vice-Chair:** Thank you. I'm sorry, we do have to move on to the Liberal caucus.

**Mr Duncan:** My colleague Mike Gravelle, who has been here all day and has some constituency meetings—we caught each other in the hall—had a couple of questions related to section (c) on pages 3 and 4. First of all, he wanted to comment that the second-last paragraph, where you talk about the Consent and Capacity Board's expanded powers in education, we fully concur with that and think it's quite consistent with the Australian model. We think makes a lot of sense.

The one concern we had with the first part of your presentation, that section, the expanded powers and taking in all kinds of new things that are currently handled by the General Division, we'd be a little bit concerned—I'd like your comments on this. Perhaps it's unfair because you're a new lawyer and new lawyers would benefit from appeal tribunals that have more powers—but we'd be a little bit worried about creating more of a quasi-judicial body that wouldn't be as accessible, particularly to the types of folks who would access it.

I think, for example, of a tribunal like the Workers' Compensation Appeals Tribunal, which has evolved into a quasi-courtroom where there are rules of evidence and precedent and all kinds of problems that were never envisioned by Weiler when he wrote his report on that. I wonder if you could comment on that and, as somebody who's beginning a long and I'm sure successful practice of law, would you not be concerned that by expanding the roles and powers you may be creating another form of court that wouldn't be accessible to the people who really need decisions?

**Ms Eccles:** I don't think so in this case, because the way the Consent and Capacity Review Board stands right now, it has the power to make rules under the SPPA, the Statutory Powers Procedure Act. So if they want to right now, subject to any legislative changes that come out of this committee, they can go to the quasi-judicial model right now. The proposal here is to just give them some more things to do basically.

**Mr Duncan:** You don't think if they had more things to do they'd have to, through the SPPA, take on to themselves a more rigid process and set of procedures governing their conduct and their decision-making?

**Ms Eccles:** Not necessarily, if the funding is there to increase the numbers on the board. The question is, are we going to pour the money into the Ontario Court (General Division) in order to do the work, or are we going to give it to the Consent and Capacity Board to do the work? Somebody has to do it, and traditionally, administrative tribunals are less rigid and less court-like than a court. Right now, the things that I've listed that are under the SDA are adjudicated in a very court-like setting, and by moving it to the Consent and Capacity Board, in my opinion anyway, it would be increasing access to it.

**The Vice-Chair:** Thank you very much, Ms Eccles. That will conclude your presentation for today. We are out of time. On behalf of the committee, I want to thank you very much. This committee is now adjourned until tomorrow morning at 9 am in Ottawa.

*The committee adjourned at 1530.*



## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

**Chair / Président:** Martiniuk, Gerry (Cambridge PC)

**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

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\*Martiniuk, Gerry (Cambridge PC)

\*Parker, John L. (York East / -Est PC)

\*Ramsay, David (Timiskaming L)

Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Orléans L) for Mr Conway

Clement, Tony (Brampton South / -Sud PC) for Mr Tilson

Duncan, Dwight (Windsor-Walkerville L) for Mr Chiarelli

Marchese, Rosario (Fort York ND) for Mr Hampton

### **Also taking part / Autres participants et participantes:**

Gravelle, Michael (Port Arthur L)

Ministry of the Attorney General

Spinks, Trudy, manager, implementation support and counsel, implementation support unit  
Ministry of Health

Perun, Halyna, counsel, legal services branch

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** Swift, Susan, research officer, Legislative Research Service

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# Official Report of Debates (Hansard)

Tuesday 13 February 1996

# Journal des débats (Hansard)

Mardi 13 février 1996

## Standing committee on administration of justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995



## Comité permanent de l'administration de la justice

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

Chair: Gerry Martiniuk  
Clerk: Donna Bryce

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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Tuesday 13 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Mardi 13 février 1996

*The committee met at 0900 in the Delta Hotel, Ottawa.*ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

## CITIZEN ADVOCACY OF OTTAWA-CARLETON

**The Chair (Mr Gerry Martiniuk):** Good morning, members of the committee, ladies and gentlemen. This morning this is a continued hearing of the standing committee on administration of justice and it's deliberations in regard to Bill 19, which is the Advocacy, Consent and Substitute Decisions Statute Law Amendment Act. We will proceed and our first submission is from Citizen Advocacy of Ottawa-Carleton, Brian Tardif. Because of the number of submissions, each submission is limited to 20 minutes including questions, and how you use your time is up to you. You may proceed.

**Mr Brian Tardif:** Good morning. I'm Brian Tardif and I'll just introduce the other two people who are with me because they're actually going to make the presentation. Beside me, to my left, is Rejeanne Lalonde. To her left is Tom Brooker. Both Rejeanne and Tom are members of the board of Citizen Advocacy. At this point I'll ask Rejeanne to take over.

**Ms Rejeanne Lalonde:** Good morning and thank you for having us. Citizen Advocacy is an organization that matches a volunteer advocate with people with disabilities or seniors who need help in some way. Because the first thing that Bill 19 does is to repeal the Advocacy Act, we're concerned with the effect that some of the proposed legislation will have on people who are vulnerable, the kind of people we serve.

We recognize that there were problems with the Advocacy Act, but we're concerned that in the process of repealing that act, some of its important elements will disappear. People with disabilities have special needs and they often have to look to others to help them fulfil those

needs, and we're talking not just about families here but about the health and social service systems and both paid and unpaid caregivers.

What the Advocacy Act did was to recognize the very existence of vulnerable people. By that we mean that there are people who don't have supportive and involved families. These are people who have to rely on paid caregivers to see to their personal care and to their quality of life. We think that the new legislation should recognize that as well.

Our first concern is that the legislation decreases the protection for consumers and increases the potential for the marginalization of people with disabilities. I'd like to give you some examples of that.

First, a single health practitioner could override the wishes of a substitute decision-maker. There's no requirement that a member of the Consent and Capacity Board be someone with expertise in evaluating capacity. It eliminates the necessity to give reasons in writing for a finding of incapacity unless it's specifically asked for, and there's no process specified to appeal the findings of the Consent and Capacity Board.

Our second concern deals with the inherent, as opposed to the relative, worth of an individual. As resources become more and more scarce, there's a likelihood the judgements on who is going to receive or not receive services or treatment will be made on the basis of the relative worth of an individual. The legislation doesn't recognize that seniors and people with disabilities will become more vulnerable as a result. This can affect all of us, given that hopefully we'll all be old some day.

A good example to give you is the young man in Alberta who had Down syndrome and who was refused an organ transplant. When that decision was examined in more detail, it became obvious that his worth to the community had been a factor in that decision. Luckily, he had a family who cared and who advocated for him.

A weakness of the legislation is the requirement for notification. The legislation requires that once a finding of incapacity has been made, a copy of the certificate of incapacity must be given to the designated incapable person by the assessor. It also indicates that the public guardian and trustee must then inform the person in a manner that is considered appropriate by the public guardian and trustee that they have become the substitute decision-maker and that the person is entitled to apply to the Consent and Capacity Board for a review of the assessor's finding.

The problem we see here is that there is no form prescribed to ensure that these notifications are made to the person who is the subject of the finding of incapacity. There's also no provision made to provide assistance to

people who might want to apply for a review of the finding to the board.

The legislation also assumes that a person is either capable or incapable. It doesn't recognize that there are degrees of incapacity; that is, that without help a person may be incapable, but that given some help, they might be able to function adequately. Also a good example of that is the case in Ontario of Justin Clark, who was institutionalized at birth and then had to go through a court process as an adult in order to get back the right to make decisions for himself. Luckily, he had community advocates who were willing to help him fight through that process.

Our third concern deals with the fact that the legislation doesn't recognize, encourage or support the role played by volunteers. In a statement by the minister of Health last July, it was stated, "The central role played by family members and volunteers in the lives of vulnerable people should be encouraged and supported." We don't think the legislation does that. The legislation mentions advice and assistance but little beyond that except that the volunteers will be protected from liability.

Considering the problems that I've talked about, these are the recommendations that we would make for changes to the bill:

(1) That the Substitute Decisions Act and the Health Care Consent Act be further amended to include a stronger recognition of vulnerable persons and provide a more balanced approach to the need for personal protection and the need for personal autonomy.

(2) That the Health Care Consent Act be amended to increase protection for consumers and decrease the potential for the marginalization of people with disabilities by:

(a) requiring the agreement of two health practitioners concerning any decision to override the decision of a substitute decision-maker, section 25;

(b) requiring that at least one member of the capacity and consent board be someone with expertise in evaluating capacity;

(c) requiring that a review of capacity be conducted by a board of at least two members at all times, subsection 71(2); and

(d) requiring that notice of finding in writing be provided at all times and not only when requested, subsection 73(4).

(3) That the Health Care Consent Act contain prescribed provisions to ensure that decisions concerning health care are made on the basis of the inherent worth and not the relative worth of an individual.

(4) That the Substitute Decisions Act be amended to provide for assistance for the vulnerable person who is the subject of the application to the Consent and Capacity Board; and that there be provisions for assistance to a vulnerable person who wishes to request a review of the decision of the Consent and Capacity Board, section 30 of the Health Care Consent Act and section 16 of the Substitute Decisions Act.

(5) That, where an application for incapacity is filed, the process for notifying the vulnerable person of the application be prescribed in the legislation to protect vulnerable adults.

(6) That the role of volunteers and voluntary organizations with respect to the Substitute Decisions Act and the Health Care Consent Act be encouraged and supported by:

(a) more clearly articulating in the legislation what roles and responsibilities could be mandated to voluntary organizations, subsection 87(1) of the Substitute Decisions Act; and

(b) specifying the roles and responsibilities that could be undertaken by volunteers, subsections 87(1) and (2).

We'd be happy to answer any questions in the time that we have left.

0910

**Mr Ron Johnson (Brantford):** Thank you very much for your presentation. I notice that your group really has done some admirable work in the advocacy area. I want to get to some solutions here with respect to advocacy work, because there's absolutely no debate around this table as to its importance; I guess really it's the methodology that we go about providing that service. How do you see us being able to incorporate all of the community groups that do a lot of very fine work in the field of advocacy, get them kind of working together without creating this bureaucracy to the tune of millions of dollars? How do you see us addressing that?

**Mr Tardif:** I'm not sure that anybody's going to have the perfect answer at this table, but I guess there are all kinds of groups in the province that do advocacy. Some of them do what Citizen Advocacy does in the form of individual advocacy, and others do systemic advocacy. Maybe it might be important to start with looking at the different levels of advocacy and creating maybe some umbrella groups there, as opposed to one large umbrella group for all of it. That's a possibility.

We at Citizen Advocacy are most concerned with the individual, as opposed to the systemic, so I would tend to think that where we would want to see any action taken is with respect to strengthening and supporting advocacy assistance for individuals. Not to say that the systemic stuff isn't important, but that's where our experience lies and that's where I guess our expertise lies.

**Mr John L. Parker (York East):** You make a specific recommendation concerning subsection 87(1) of the SDA and the role for volunteer groups. As one such group yourselves, can you assist us with what sort of role you would like to see yourselves given in the statute?

**Mr Tardif:** I would say that the volunteers, certainly volunteer advocates who are involved with Citizen Advocacy, not just in Ottawa but in lots of other Citizen Advocacy organizations in this province and elsewhere, what they do is they provide a very personal approach to a vulnerable person's difficulties. So we talk about how Bill 19 depersonalizes the approach to a substitute decision-maker being appointed and the approach to a finding of capacity or incapacity. A volunteer can provide the assistance that a person might require or wish to have in those deliberations.

The other thing is, when we're talking about people who are really vulnerable, what we're finding is that it's the volunteer advocates who are the people who are watching out for them, because they don't have anyone else. Quite frankly, they're doing it, but they don't have



any real authority to do it. I think that's one of the main gaps that exists at the moment.

**Mrs Elinor Caplan (Oriole):** I'd like you to be a little more specific as to the kinds of amendments that would achieve your objectives, given the fact that the government is determined to eliminate the entire Advocacy Act as part of this bill. What sections do you think should be amended that would give the protections for vulnerable people that you're looking for?

I understand where it is as far as giving them information and helping them to make an appeal, and I think those areas can be strengthened. But you made quite a general statement, "to increase protection for consumers and to decrease the potential for the marginalization of people with disabilities," and you've stated four areas. I'm wondering whether you have any specific amendments other than those four areas that would assist, for example, in areas of education for providers or for families or for patient consumers themselves. There's no mandate for anyone to do any education in this legislation. Have you thought about that at all?

**Ms Lalonde:** The elements we have thought about are either in the presentation I've made this morning or they are in the brief, although I have tried to summarize the brief we have given you. Those are the elements that we think are the most important. I don't know of any other specific recommendations we could make, although we would certainly be happy to give it another look and try to come up with some.

**Mrs Caplan:** I think your first recommendation is a particularly important one, where it says, "That the Substitute Decisions Act and the Health Care Consent Act be further amended to include stronger recognition of vulnerable persons and provide a more balanced approach to the need for personal protection and the need for personal autonomy." Many of the safeguards have been removed from the legislation. It in fact weakens that, but you haven't been specific as to which ones you'd like to see put back in, outside of having an Advocacy Act. If you'd like to think about that and give us your suggestions, I'd be happy to hear them.

**Ms Lalonde:** We would certainly be happy to do that.

**Mrs Caplan:** Also, I'd like to know, when you talk about volunteers, I think that's extremely important. Certainly they've been the backbone of providing assistance to vulnerable people for many, many years. One of the concerns that I have, however, is in the area of training, because sometimes, as well meaning as we can be, unless people receive the kind of training, then I don't think they're as valuable in providing that assistance. I wondered if you thought about that at all.

**Ms Lalonde:** Certainly, as an organization, we are very concerned with the quality of advocacy and supports that our volunteers provide. I'll leave to Brian the care of telling exactly how we achieve that.

**The Chair:** The time is up to answer that question. I'm sorry. Mr Marchese.

**Mr Rosario Marchese (Fort York):** Thank you for your submission. I wanted to highlight a few things that a number of other people have been saying. Because we don't get too much time to ask people questions, they simply don't get to be highlighted, but there have been a

number of people who have been saying, "requiring that notice of finding in writing be provided at all times," which is in the existing legislation, and that's been removed.

"Requiring that a review of capacity be conducted by a board of at least two members." There have been a number of people already who have spoken about that, particularly consumer survivors, who have said that it's terrible to have to rely on just one person for a determination of your capacity or incapacity and that's frightening. So people have been saying that.

Your recommendations 4 and 5 as well are consistent, where people have been saying, "We need advocacy and we need rights advisers, in whatever form, and if you can't accept the Advocacy Act as we have it with the Advocacy Commission, we still need advocacy and rights advisers." We've been getting a number of suggestions from people on how to do that. It would be, in my view, almost unconscionable that this government would not act on that, given that 95% of all the deputations have said, "We need that." So I thank you for that kind of support.

Doctors have been saying that it would be harmful to give rights advice to patients, that given their condition, if they had informed them of the kind of problem connected to incapacity, that could do more harm to them. The other point they made was that doctors are not lawyers and rights advice is almost a legal matter, not something that they normally do or I guess should do. Do you think that not giving information to people might be in fact more harmful than to do the opposite, that not to give them information is more harmful than to withhold information?

**Ms Lalonde:** I'm certainly not a psychologist or a psychiatrist to determine what is going to do mental harm to another individual. However, as an organization, we believe the people we work with are capable of making decisions in a lot of cases and we give them the benefit of the doubt. I'm not sure it's up to the government or to anybody else to determine that I as an individual don't have the capability to make decisions for myself until that decision has been made in some kind of impartial and objective venue. So I would err on the side of giving information to an individual whose life is involved.

**The Chair:** Thank you very much. Your time is up. We appreciate you condensing your written submission and that'll be reviewed by the committee.

0920

EARL ATNIKOV

**The Chair:** Mr Atnikov.

**Mr Dwight Duncan (Windsor-Walkerville):** Mr Chairman, my agenda's showing Mr Capelle.

**The Chair:** Yes, it's been changed.

**Mr Duncan:** What was his name again? I'm sorry.

**The Chair:** Atnikov. You are in place of Mr Phillip Capelle?

**Mr Earl Atnikov:** Yes, Mr Chairman. I've been slotted in at the last moment, if I may.

Thank you, Mr Chairman, honourable members. On behalf of the members of the local bar in Ottawa repre-



senting patients and review boards, I am pleased to have this opportunity to address some of the concerns we have with respect to the proposed amendments and their effect on perhaps the most vulnerable population in our community.

If we as a province and as a community are to be judged by the manner in which we treat the weakest and most disfranchised among us, I fear that these proposals will leave us wanting in the eyes of our children, and indeed it is our children who may use these very amendments to deny us basic rights and freedoms without meaningful recourse or protection.

The broad language setting out the purposes of the Health Care Consent Act, and I'm referring to clause 1(c) and 1(d), "to enhance the autonomy of persons for whom treatment is proposed..." and "to promote communication and understanding between health practitioners and their patients or clients," is, in our respectful view, not realized by the legislation in its current form and will often fly in the face of another stated purpose, that is, of clause 1(e), "to ensure a significant role for supportive family members when a person lacks...capacity."

In my reading of the proposals as drafted, emphasis is placed on a paternalistic health care system and individuals' families to make decisions regarding admission and treatment to care facilities. These take precedence over the individual's wishes, and the purpose appears to be to allow simply for administrative ease over those rights we all hold very dear.

It is our view that with these amendments, the balance has now swung back years in the protection of those who need it most. This is demonstrated in three major areas that I wish to just highlight briefly, and those are the rights advice, the makeup of the board for certain hearings and the requirement of providing written reasons.

Firstly, with respect to rights advice, equal access to the law implies knowledge of the law. We are dealing with, we must recognize, a vulnerable population whose basic freedom is at stake. We are also dealing with a population which is very impressionable. To ask of psychiatric facilities to designate persons or classes of persons to perform the functions of a rights adviser under the Mental Health Act or to appoint volunteers for this purpose or to have the minister appoint rights advisers does not adequately, in our view, ensure that these individuals are receiving independent and full and fair information regarding their rights. Indeed, it places the hospital and doctors and other facilities in a clear conflict, for it would be the psychiatric facility or doctor who has just certified that individual and restricted that individual's freedoms. While most psychiatrists are no doubt conscientious and well meaning, to expect them to provide this balanced information is expecting, in our view, simply too much. I also understand that some hospitals and doctors are clearly uncomfortable with the proposals and having been put in this position.

It's our view that an independent body is needed to provide this rights advice. It need not be the Advocacy Commission as it stands currently. There have been processes in the past that have worked rather well, including sending out, for example, lawyers on a legal aid, duty counsel basis from the legal aid office, as under the next-

to-last amendments. What we do have, however, are individuals currently who have been well trained in providing this advice in a balanced and fair manner and who will allow for individuals to make decisions to, for example, appeal or not appeal a decision of a finding of incapacity or committal.

We also request this committee to consider that Ottawa is peculiar in that we have no provincial psychiatric hospital. We are dealing in an area where there is solely acute care beds, and accordingly we have no patients' rights advocacy office.

As Ms Caplan, in questioning the previous presenter, mentioned, I think she expressed a concern with respect to having volunteers do some of this work. It's my feeling that volunteers simply, without any training, are not in the position to provide this very needed service.

Beyond the advice itself, there is section 75 of the Health Care Consent Act, with reference to individuals being represented by counsel or agents. We feel that, given the seriousness of the consequences for individuals before a board, individuals should be allowed access, and in fact guaranteed access, to counsel, including legal aid, if otherwise qualified.

Second on our agenda is subsection 71(2) of the proposed Health Care Consent Act, which allows a single member of a board to sit alone in dealing with issues of capacity. As the previous presenter indicated as well, there is concern that that poses some concerns, given the fact that there may not be any particular expertise in that individual to make decisions of capacity. We must recognize that these decisions are far-reaching and have serious consequences to the individual. In talking to members on boards and doctors, I believe it's the general feeling that the expertise of, for example, psychiatrists, in assistance and guidance to the board in dealing with such issues would be invaluable. In our view, again it's a demonstration of the administrative ease that has taken precedence over an individual's rights and the ability to pursue those rights in a fair manner.

Thirdly, subsection 73(4) of the act requires the board to issue written reasons only on the request of a party. While we anticipate that if counsel were present, they would be a regular occurrence, the written reasons would be requested in every situation, the question I simply put to the committee is why the onus would be shifted to the individual to request reasons for a decision to in effect restrain one's freedoms, especially where that person may indeed not be represented by counsel. When we are dealing so intimately with the security of the person as we are in these situations, we find this proposal reflects the tenor of the legislation as a whole, which is to facilitate the placement and treatment of individuals at the expense of a fair protection for individuals under the law.

Those are my comments. I thank you for this opportunity and I hope this has been of assistance.

0930

**Mr David Ramsay (Timiskaming):** Thank you for your presentation. I'd like to narrow in on rights advice and just try to clarify what you're saying. As you know, under the present legislation, after a finding of incapacity the onus is on the person who made that declaration to advise the patient that he has the right to appeal that.



That's not there, as you pointed out, in the legislation we're talking about today, the Health Care Consent Act. I just want to be clear: Who exactly do you feel now should give the rights advice?

**Mr Atnikov:** The situation we have currently is with the Advocacy Commission, where they have trained individuals, trained rights advisers, to provide that information. That seems to have been working fairly well. In the past it was lawyers going out as duty counsel, and as required by the previous Mental Health Act under the legislation legal aid lawyers were going out, again an independent body. It matters perhaps less as to who is actually doing it; it's just that they'd be properly trained and independent and provide a fair and balanced indication of an individual's rights.

**Mr Ramsay:** So there would have to be some sort of mechanism that once the health care professional makes that decision, then somebody would have to be notified, this independent rights adviser, and then that person would come in and talk to the patient.

**Mr Atnikov:** I think there must be a mechanism where notification in every case, for every decision in effect that restricts an individual's basic freedoms, must be in place.

**Mrs Marion Boyd (London Centre):** Thank you for your presentation. I can understand entirely why the local bar would be concerned about the situation in terms of the lack of rights advice. You made the comment that you felt most of these amendments really were showing that the government was looking at administrative simplicity, and I would add financial savings, as opposed to individual rights. I think that is the real danger. From your perspective as a lawyer, do you not think that's a fairly short-term saving in the long run? Don't you really agree that in the long run the kinds of challenges to this sort of ignoring rights is going to be more expensive?

**Mr Atnikov:** I think there's a real question of whether some of this will hold up under certain challenges before the courts. The stated purpose of the proposed legislation, to ensure significant rural support of family members, in some cases, perhaps in many of the cases, misses the point of the kind of population we're dealing with here. In effect, I think it's just marginalizing further an already very weakened, disfranchised segment of our community, at great risks to the community as a whole. That's really the emphasis that I would like to stress.

**Mrs Boyd:** Particularity this issue of having a single member alone, with no requirement that any member of a board, whether it was the three members or two or one, have any particular expertise. When you look at a single member with no expertise in the assessment of capacity, it certainly gives rise to a great deal of concern among vulnerable communities because they've been taken advantage of before, have they not?

**Mr Atnikov:** I think a lot of individuals I've run across in my practice would say they've been taken advantage of. To have, for example, a doctor give certain advice probably places that doctor in a more difficult situation with the patient, with the client, and defeats again one of the stated purposes of the legislation.

**Mrs Boyd:** It's really difficult, isn't it, knowing the population that is affected and knowing the vulnerability. This whole issue that first of all they're not necessarily

being informed that they're incapable, and then not necessarily being informed that there's any appeal against that finding, and then not having any way to ensure that substitute decision-makers are being honoured in the system. The whole thing is really very difficult, isn't it?

**Mr Atnikov:** I find it difficult. Thank you, Mrs Boyd.

**Mrs Helen Johns (Huron):** I just wanted to draw your attention to the Mental Health Act, that basically stated that rights advisers for government-run psychiatric hospitals had to be government employees, part of the PPAO. From other psychiatric institutions, those people would be set by regulations, but it is certainly our intention not to have someone involved who is a member of the clinical team. We would have someone, ie, the chaplain or someone who is on another team. I think we address your interest there.

I was very interested in your comments about the Consent and Capacity Board and the one-member team. We put this one-member team in because it was very difficult, in rural and northern Ontario, to get the board together in a very timely manner. In fact, in some cases it's taking seven days to get someone. When you said the person had to have really no qualifications, I'd like to draw your attention to 71(2)(a) through (d), which says the person has to be a lawyer, has to be a member of the Ontario bar for at least 10 years, has to have been on the board for at least two years so has seen this process go through a number of times, and possesses any other qualifications set by the board.

I think those are pretty substantial qualifications and I somewhat take issue to the fact that you said they don't have qualifications. Do you want to comment on that?

**Mr Atnikov:** It says the chair may set certain qualifications. Those aren't outlined in the act and I haven't seen the regulations.

**Mrs Boyd:** No one has.

**Mr Atnikov:** That leaves me with some concern.

**Mrs Johns:** Clauses 71(2)(a) through (d). Those are not the regulations. That's the legislation.

**Mr Atnikov:** But (d) says "he or she meets all of the other qualifications specified by the chair."

**Mrs Johns:** Yes, but she or he at least has to be a lawyer, has to be from the Ontario bar and has to have two years of work on the board. Those are pretty substantial qualifications.

**Mr Garry J. Guzzo (Ottawa-Rideau):** It depends where you're sitting.

**Mr Atnikov:** When you're dealing with issues of capacity, I think there's a particular expertise that one would want to bring to the board. I'm not saying that it isn't there or it won't be there. I'm saying there's more of a concern, when you're dealing with one person who is making a decision, with far-reaching consequences to an individual who may or may not be qualified. I'm not saying that in all cases they won't be qualified.

In terms of why a one-person board might be composed for regions, say, in northern Ontario, frankly, if seven days is what it takes for a hearing to be held, then seven days is what it is. I think when you're dealing with an individual's decisions and taking those decisions away from that individual—excuse me, sir?



**Mr Frank Klees (York-Mackenzie):** What about the patient?

**The Chair:** I'm sorry. Mr Atnikov, I thank you for your presentation.

#### ALZHEIMER SOCIETY OF OTTAWA-CARLETON

**The Chair:** The next submission is the Alzheimer Society of Ottawa-Carleton, Ms Kathy Wright, executive director. Welcome. Could you identify the other individuals who might take part in the presentation for the purpose of Hansard.

**Ms Kathy Wright:** This is Nadia Diakun-Thibault, who will be actually making the presentation. I apologize, I did call on Friday to give that information. Nadia is a former board member and current member of the Alzheimer society and served on our public policy committee for many years. On my far left is Pat Murphy, who is on our board of directors and is our legal counsel.

**Ms Nadia Diakun-Thibault:** Thank you, Mr Chair. With your package, you have received from us a clause-by-clause discussion and some points and some of our concerns as they are reflected in Bill 19. You can read those at your leisure. We trust that you'll take them into serious consideration.

*Interruption.*

0940

**Ms Diakun-Thibault:** I hope that's not the Premier calling from Hong Kong.

The Alzheimer Society of Ottawa-Carleton exists to increase the understanding of, and most effectively alleviate, the personal and social consequences of Alzheimer disease through patient and family support, information, education and promotion of research. Alzheimer disease is a disorder of the brain causing loss of memory and serious mental deterioration.

At first, the person with Alzheimer disease exhibits only minor, almost imperceptible symptoms that are often attributed to other illnesses. As memory loss increases, changes also appear in personality, mood and behaviour. It may take longer to complete a simple chore; judgement, concentration, speech and physical coordination may also be affected. The symptoms are usually progressive, but there is a great variation in the rate of change from person to person. The person with Alzheimer disease is often unaware of or may deny the full extent of his or her limitations.

The illness is a source of deep frustration for both those afflicted and for their loved ones. Caring for an Alzheimer person is a 36-hour-a-day job. An estimated 300,000 are affected in Canada; approximately 7,000 persons in the Ottawa-Carleton region have Alzheimer disease.

The fluctuating capacity of an Alzheimer person, the absence of a definitive test for Alzheimer disease in early stages and the ever-decreasing capability of the "sandwich generation" to care for their aging parents in the light of their own aging have placed a tremendous socioeconomic strain on many families. There aren't enough facilities to care for Alzheimer persons in a manner that would address their particular needs.

We must consider those with Alzheimer disease as incapable of granting consent to treatment and to manage their property. Whatever capacities the person may retain throughout the steady progression of the disease, these become more and more limited as to make decisional participation moot.

Bill 19 proposes changes to the Substitute Decisions Act and Consent to Treatment Act which in our opinion may have a deleterious effect on persons with Alzheimer disease and their families. We see some of the provisions of Bill 19, the Health Care Consent Act, as weighted in favour of the health practitioner, the care facility and the personal assistance plan manager rather than the substitute decision-maker, often a family member.

First, we would like to dispel the notion that there are many treatments that pose little risk or harm. The understanding of risk or harm is relative to the individual. Changing the formulation of a prescription for persons in their twenties may pose no additional risk, while such a change could be serious for a geriatric patient. What is considered the statistical or clinical norm is not necessarily applicable to the elderly. Consider a non-invasive diagnostic test such as a CT scan or MRI, which requires the cooperation of the patient. For the cognitively impaired person, executing simple commands is often extremely difficult.

Subsections 19(2)(c)1(ii) and (iii) and companion sections 40 and 57 effectively suggest that if a treatment is likely to "reduce the extent to which, or the rate at which, the incapable person's condition or wellbeing is likely to deteriorate" the health practitioner is given an override of a substitute decision-maker's right to refuse such treatment on behalf of an incapable person.

For example, the patient is an 86-year-old Alzheimer person in respiratory distress. The treatment proposed is intubation and placement on a ventilator to facilitate respiration, and the likelihood of this being a temporary measure is slim. This course effectively prolongs life for a seriously debilitated individual. The substitute decision-maker refuses consent to intubation and asks that palliative care be administered instead. Section 35 allows the health practitioner to claim that it was an emergency, allege non-compliance with section 19 and apply to the Consent and Capacity Review Board.

The board may substitute its opinion for that of the substitute decision-maker and give directions, and if the substitute decision-maker does not comply with the board, then the substitute decision-maker is deemed not to be authorized to give or refuse consent on the incapable person's behalf. The board's ruling would not be based on evidence of fact but would be rendering judgements of compliance or non-compliance based on principles of medical ethics, bioethics, moral autonomy.

What gives an administrative tribunal the right of a court to override a legally executed document, such as a power of attorney for personal care, perhaps with an appended advance medical directive? In our opinion, such a contrary action on the part of a health practitioner in the case we have illustrated would have deleterious effects on both the person and the family.

The long-standing common law provision of a person's right of self-determination must be preserved. The com-



mon law provision of informed consent must be upheld, and a person's wishes in the event of irreversible incapacity regardless of causation must be honoured.

By granting such decision-making powers to the Consent and Capacity Board, the Legislature is subdelegating a power to an administrative tribunal that is more properly in the domain of the courts. Decisions rendered under section 35 would set precedent.

Inasmuch as the Consent and Capacity Board is also given the power to sit in a panel of one, three or five and the decision of a panel of one shall be deemed as the decision of the board, is it the intention of your government to change the very nature of dispute adjudication away from the court, where strict rules of evidence apply, to place it where "in the opinion of the health practitioner" carries greater weight than fact? Is it the intention of your government to delegate matters of consent to treatment to a panel of one and have the force of common-law precedence?

Matters of consent, determinations of decisional capacity and incapacity on property and personal care are too grave to be decided by a panel of one and rendered in 24 hours.

This bill further implies, albeit not explicitly, that adequate care for incapable persons is possible in the home. Section 40 and companion compliance section 52 could be used to refuse the admission of an Alzheimer person to a care facility because, in the opinion of the evaluator, the Alzheimer person's quality of life would be better in the home rather than in a care facility.

For those who suggest that there are adequate community supports, such as day-away programs, Meals on Wheels etc, think again. Your government has proposed serious reductions to community and social programs. If this were your parent, your spouse, would you be able to care for the person at home in the face of economic hardship or your own reduced capability to provide around-the-clock care? It is a statistical fact that elder care in Canada is provided primarily by spouses—females—daughters, daughters-in-law, granddaughters. Is it the intention of this government to disadvantage women?

Bill 19 proscribes the use of appropriate monitoring devices or means of chemical or physical restraints. Alzheimer persons often have excess pent-up energy and wander. Their somewhat difficult behaviour could be used as a cause for their deinstitutionalization, as it were, from a care facility, to be sent home or other place, citing this section. Anxiety and agitation, often common among persons with Alzheimer disease, is not necessarily a threat of bodily harm to themselves or others, and low doses of neuroleptics can help control the condition.

It would seem that this section could be applied to such security devices as door alarms, perimeter alarms, secure floors. Is it the intention of this government to force the care of persons in early stages of Alzheimer disease to be provided in the home until such time as the person's condition has deteriorated to the point they are no longer ambulatory?

Bill 19 proposes to remove conditions currently found in section 16 of the act, conditions which stipulate that an assessment should not be performed unless the assessor first explains to the person the purpose of the assessment,

the significance and effect of a certificate of incapacity and the person's right to refuse to be assessed.

In the early stages of Alzheimer disease, the person maintains varying degrees of comprehension and appreciation. This fluctuating capacity is difficult to work with. Regardless, the person is entitled to be properly informed.

This bill outlines that evaluators shall be persons as defined: audiologist/speech-language pathologist; nurse; occupational therapist; physician/surgeon; physiotherapist; psychologist.

By virtue of the evaluators' belonging to a particular professional college does not automatically qualify them to determine capacity for admission to a care facility. What assurance will be given that such evaluators will be properly trained to perform a capacity assessment? Would anyone—any one of you, perhaps—readily agree to have capacity determined by a family physician with little knowledge of neurology?

Certification of evaluators must assure the public that they are fully qualified to carry out the rigours of capacity assessment and minimize error and inaccurate assessments. It is not enough to use the principle of fiscal responsibility in an effort to lower the cost of assessments by broadening the class of assessors without strict regulations, guidelines and criteria for certification.

Bill 19 also seems to propose that a person who provides health care and residential, social and training or support services may hold a power of attorney for property or a power of attorney for personal care on behalf of a patient, resident, client, with the exceptions of statutory guardianship of property or person.

It is a pecuniary conflict of interest for the owner of a residential care facility or administrator of a home for the aged to hold a power of attorney for property on behalf of a resident. It is an ethical conflict of interest for a health practitioner to hold a power of attorney for personal care on behalf of a patient.

The proposed amendment to 57(1) seems to fetter the court in its consideration of the public guardian and trustee. That would seem to be *ultra vires* the Legislature. The state has a duty and obligation to its citizens to protect their welfare. For those incapable persons without family or persons willing to act as their guardians of property or the person, removing the PGT abrogates that obligation.

#### 0950

Section 58 repeals sections 87 and 88 and makes provision for "volunteers to provide advice and assistance" to the public guardian and trustee under the act. Just what does this mean? Volunteer rights advisers, volunteer guardians of property, volunteer guardians of person, volunteer advocates? Then further, no liability "for any act done in good faith in the execution or intended execution of the volunteer's powers and duties"?

The public guardian and trustee should not require volunteers or conduct any business using volunteer help, not even for clerical duties. It would jeopardize the confidentiality of records, which could be seen by persons who are not accountable. It is inappropriate for the crown to engage in volunteerism within the Ministry of the Attorney General and to extend immunity to persons who are not directly employed by the ministry.

The minister has every opportunity and right, without a specific clause in statute, to invite persons to provide advice on policy or other matters. Advice and opinion may be accepted or rejected.

We hope that the notion of volunteers performing duties for the public guardian and trustee is not a half-hearted effort and gesture on the part of this government to placate supporters of an advocacy system on behalf of vulnerable persons. We believe in advocacy for the elderly, especially for persons with Alzheimer disease and their families. We do not, however, support the use of volunteers at PGT.

In delivering the certificate of incapacity, there are no safeguards to protect the confidentiality of the person, to assure that the notice will not fall into the wrong hands, to assure that the contents and effect of the notice will be communicated to the person and the substitute decision-maker, albeit that the person may not comprehend or be able to read the document, and done so in a proper fashion.

The Alzheimer Society of Ottawa-Carleton firmly supports the principle that government intervention should be the last resort. We firmly support the principle of informed consent and appreciate well the challenge and difficulties of applying it to an Alzheimer case. The nature of neurological disorders makes it very difficult to implement informed consent in a very meaningful way, and therefore it is incumbent upon the health practitioner and others to be well prepared when dealing with a patient with cognitive impairments. If the revisions to the Consent to Treatment Act are to be in any way useful, the application of the act must be rational and realistic.

It would be prudent for this government, considering the increasing numbers of elderly in the province and the inevitable aging of the baby-boomers, to initiate policies that will address future needs. Such a visionary approach could begin with the establishment of an office of the Ombudsman for the elderly to tackle such problems as elder abuse. It would be prudent for this government to take demographic data seriously as a statement of the future. It would be common sense.

**Mrs Boyd:** Thank you very much for your presentation. The concerns that you've mentioned about confidentiality, about the need for appropriate information—

**Ms Diakun-Thibault:** I'm sorry, Mr Chair. I cannot hear the member.

**The Chair:** You'll have to speak a little louder, Mrs Boyd, I guess.

**Mrs Boyd:** I think it was the noise on the other side of the table, Mr Chair.

Thank you for your presentation. The concerns you've expressed about privacy of information and about the override by physicians of substitute decision-makers, given the sections that allow the physician to apply to the board, just on a belief that the person may not be following those rules under an advanced directive, are quite concerning to a lot of people. But you've expressed it much more forcefully and clearly than many groups that have come before us and it's very helpful for us.

I noticed that you've appended a clause-by-clause section which will be very, very helpful to us as we go

through the clause-by-clause and I really thank you for doing that, because it represents a lot of work.

I guess the one thing we hear from you is that families may be caring and loving and wanting to help, but the expectation that they can do that on a 24-hour-a-day, seven-day-a-week basis—in fact you described it as 36 hours a day and I understand what you mean—is not very realistic. Every time someone comes before this committee and talks about the need for rights advice and for advocacy at arm's length and apart from the family, the government starts talking about this mythical family that can manage all these sorts of things. So thank you for making those comments.

**Mr Tony Clement (Brampton South):** Thank you very much for your comments. I wanted to say just right off the top that you've raised some very serious concerns from your perspective and we'll have to review the legislation as we go through this process, because it certainly was not the intention to disadvantage women, to create a structure which was going to disadvantage victims of Alzheimer disease. We'll review the legislation from your eyes and ensure that that is not the case.

**Ms Diakun-Thibault:** Excuse me. We'll be waiting for the amendments very eagerly.

**Mr Clement:** We'll be reviewing it from our perspective and see whether your view is valid or invalid according to our perspective, and that's what the legislative process is all about. But I thank you for your input.

I just wanted to talk about section 35 once more, because you reference very, very quickly in your paper section 19, which is what section 35 refers to, to see whether the health practitioner views the practice that is being supported by the substitute decision-maker as being within the bounds of section 19.

If you look at section 19, as I'm sure you have, you'll realize that the values and beliefs of the vulnerable person are very much first and foremost in considering what's in the best interests of that vulnerable person. I'm just wondering whether you've taken that into consideration in your remarks, because it seems that we have covered off that particular concern and have ensured that the substitute decision-maker is not overruled just willy-nilly. It has to be in reference to what's in the best interests of the person.

**Ms Diakun-Thibault:** I have read sections 19, 40 and 57, respectively. They are clones of each other with modifications. I have read section 19 perhaps now 500 times, and that's not a light number that I would say, because I wanted to make sure that I understood what the implications were.

The seminal difference is—

**The Chair:** Sorry. Mr Clement, I'm sorry, your time is up. I'm sorry, ma'am.

**Mrs Caplan:** We'll use our time to let her finish that question.

**Mr Duncan:** Yes, could you please continue.

**Ms Diakun-Thibault:** Thank you very much. I appreciate that. The seminal difference between section 19 as it appears in this bill and as it was in the previous bill is 19(2)(c)1ii and iii; (c) is the addition. In our reading, it seems to suggest that it goes far beyond simple considerations of the wishes of the vulnerable person. There is an



implicit judgemental suggestion that a health practitioner has greater and better judgement by virtue of education or training. I do not think that that is necessarily the case. I think that in some instances this may be correct and it might be applicable. However, I think that if there is a valid power of attorney for personal care and explicit advance medical directives, there is no need for that section whatsoever and no need to second-guess the substitute decision-maker nor the person who has expressed those wishes.

**Mr Duncan:** I'm new to this, and I just want to make sure I understood all the proposed amendments you have. What you're suggesting to this committee is that the bill gives too much power to health providers and not enough either to victims or their families in supports and that the proposals you've outlined will help set those balances in better order. Is that correct?

**Ms Diakun-Thibault:** Yes. If it is the intention of the bill, as it says in its preamble, to facilitate communication, then please do so. I don't see that suggestion in the proposed changes.

**The Chair:** Thank you for your presentation.

#### REAL WOMEN OF CANADA

**The Chair:** The next submission is from REAL Women of Canada. Perhaps you could identify yourselves for the purpose of Hansard.

**Ms Diane Watts:** My name is Diane Watts. I'm a researcher with REAL Women of Canada, and this is Sophie Joannou, on the board of directors of REAL Women of Canada.

We make four recommendations, you'll note, at the end of our brief: the age of consent for minors to be set at 16 years of age; families to participate as a right in all applications to the Consent and Capacity Board; when a partner's substitute consent is given, there should be a requirement that the incapable person's family be notified and consulted; and the "best interests" of an incapable person should include a presumption in support for treatment and an application to the Consent and Capacity Board be required before any withdrawal of treatment occurs. I'll try to explain that as I go along.

**1000**

Realistic, Equal, Active for Life: Those are the meanings of REAL in our name, REAL Women of Canada. We're a non-partisan, interdenominational organization of independent women, federally incorporated in 1983. We come from all walks of life, occupations, social and economic backgrounds. We promote equality for all women, the concept of which is expressed in the E in our acronym, REAL Women. One of the objectives is to support policies for women that provide equal opportunity in education, employment and retirement. We believe that the social and economic problems of women today should be resolved by taking into consideration their impact not only on the woman but also on the family and society as a whole.

Thank you for this opportunity to appear before this committee today.

We are pleased that as stated in clause 1(e) of Bill 19, one of the objectives of this bill as set out is to ensure

that supportive family members have a role when a person lacks the capacity to make his or her own medical decisions.

Unfortunately, however, it would appear that this legislation does not, in several important respects, provide this role for the family. In particular, we refer to the failure to include in the legislation a role for parents in their children's medical treatment and in regard to applications to the Consent and Capacity Board.

Our association is shocked that Bill 19 fails to provide an age at which a child would be presumed not to have the capacity to make a decision in regard to health care. This omission is destructive to the family unit as well as to the wellbeing of the child.

Subsection 3(2): "A person is presumed to be capable with respect to treatment, admission to a care facility and a personal assistance plan." Section 9 gives the health practitioner the right to treatment.

It is clear from these two sections that the health practitioner has the sole authority to determine whether anyone, including a child of any age, has the capacity to give consent for medical treatment. This is an unbelievably wide power given to health practitioners, who, according to the definition in section 2, include chiropractors, masseurs and naturopaths and who may be complete strangers to the child. Treatment is defined in section 2 to include "therapeutic" and "preventive" services. The health practitioner may also determine the child's capacity to consent for cosmetic services.

In the second paragraph on page 4, we note that the failure to provide a cutoff age for a child's consent creates the absolute absurdity in practice of a parent's consent being required to permit that child to participate in a field trip at school but not for major surgery. The age of 16 is required for driving a car, voting; the purchase of cigarettes and alcohol requires adolescents to be 18 or 19. Why then the exception in medical treatment—the decision in this regard having long-range ramifications throughout the child's life.

Failure to provide a role for parents in the child's medical treatment appears to be inconsistent with other parts of the bill. Several sections mention 16 years of age—sections 18, 19, 22, 31—in various situations.

Common sense indicates that children do not have the same experience or decision-making skills as adults. They are frequently not aware of the family medical history or the risk elements involved. Procedures such as those operating abortion clinics, who after all are in the business of making profit—this refers to health care practitioners—it is certainly in their financial interest to find such minors capable to make such a decision. It is particularly disturbing that abortion entrepreneurs have this decision-making power, considering the fact that teenagers, particularly young ones, are subject to greater risks in abortion procedures than older women, and we give a source for that.

Parents have known a child for his or her entire lifetime and, in most cases, display a superior protective instinct commonly understood to flow naturally from the parent-child relationship itself.

On page 6, we mention that it should be pointed out that the Ontario Association of Children's Aid Societies

protested the radical change in philosophy apparent in the bill's predecessor, the Consent to Treatment Act, which also included a bias in favour of a child's emancipation over the rights of the parents. I'll quote from that statement:

"We...feel the need to point out that the Consent to Treatment Act makes radical changes to provincial legislation and policy with reference to all families and in particular the responsibilities of all parents in Ontario.... We strongly object to the failure of this legislation to respect...the legitimate and necessary role of parents in the first instance with respect to supporting the medical needs of their children."

So this is what we see happening: again, increased power on the part of the health practitioner.

Parents are placed in a difficult position. They have under this bill the onus of law of proving that the child is not capable of understanding proposed treatment. Since they were not present at the consultation by the health practitioner, parents are therefore put at a distinct disadvantage. On the other hand, if the bill included a presumption of incapacity for all those children under 16, this would reverse the onus, putting it back in the hands of the health provider who wishes to provide such treatment.

Moreover, the parent is doubly disadvantaged in Bill 19 by the fact that section 27 of the bill provides that the health practitioner need only declare that he "believes, on reasonable grounds and in good faith," that the minor child has the capacity to give consent and he is then given full protection from liability. The parent therefore is not even provided with an opportunity to legally challenge the health provider's decision. That is, under this bill the health practitioner has full protection and the parent of a minor child has none at all. This is indeed a travesty of due process, not only for the family, but for the child and society as well. It constitutes an injustice so grave that it undermines the entire credibility of the bill.

The unconstitutionality of Bill 19 as to a minor's capacity: We refer you to a case in the Supreme Court in January 1995 stating that the court concluded that the rights of parents, including that of deciding medical and other treatments, are a fundamental aspect of freedom of religion guaranteed by section 2(a) of the Charter of Rights. I'll read off Mr Justice La Forest's statements:

"Although [in Canada, a parent's] liberty interest is not a parent right tantamount to a right of property in children, our society is far from having repudiated the privileged role parents exercise in the upbringing of their children. This role translates into a protected sphere of parental decision-making which is rooted in the presumption that parents should make important decision affecting their children because parents are more likely to appreciate the best interests of their children and because the state is ill equipped to make such decisions itself.... I would have thought it plain that the right to nurture a child, to care for its development, and to make decisions for it in fundamental matters such as medical care, are part of the liberty interest of a parent."

Not only is the failure to provide a cutoff age for a child's consent wrong in policy, but it would appear to be wrong in law, as well.

The family is excluded from application to Consent and Capacity Board. In subsection 9(1) the health practitioner is given the singular responsibility of determining whether an individual has the capacity to give her or her consent. It's a departure from the previous Consent to Treatment Act. This does not provide sufficient protection for a child or an adult from a health practitioner's possible bias in support of withholding treatment owing to economic considerations, or perhaps a bias in support of birth control or abortions for minors, even though they may be directly contrary to the family's values and religious beliefs. This can only lead to disharmony and heartache for the family.

#### 1010

Regrettably, as stated previously, there is no way a family member can appeal any decision of a health care practitioner. The individual and the health practitioner have as a right the authority to be a party to the application. The family may participate, however, only if the board so specifies under subsection 30(3) of the bill. Who then is to be the spokesperson for the vulnerable person? Surely the family, who know and understand the background of that individual and who would be most personally affected by any decision of the board, should have as a right the choice to participate in the hearings. The same argument applies as well to the provision of section 32 of the bill in regard to an application in regard to a person's admission to a hospital. Sections 34, 48 and 63 also fail to provide for the family in applications to the board.

Finally, this failure to include the family in the appeal process would appear to be in direct conflict with clause 1(e) of the bill, which provides as follows:

"1. The purposes of this act are...

"(e) to ensure a significant role for supportive family members when a person lacks the capacity to make a decision about a treatment, admission to a care facility or a personal assistance plan..."

Consent of "partner" in giving consent: Our association has some concerns about paragraph 4 of section 18, which provides that a partner may give a substitute consent for an incapable person's treatment. Partners are defined in subsection 18(9) as two persons who "have lived together for at least one year and have a close personal relationship that is of primary importance in both persons' lives." This section does not provide that these partners be of the opposite sex.

Our concern lies in the fact that this "partner," a relationship consisting of an association of only a minimum of one year, takes precedence over subsection 18(3), over all family members. This would appear to be an unduly harsh provision in that it excludes the family from a very sensitive and crucial decision and gives a partner the total decision-making authority. At the very least, this proposed legislation should require that a family member be notified and consulted in regard to the decision if a family member is available.

The "best interests" doctrine: It is noted that section 34 provides that the substitute decision-maker may apply to the Consent and Capacity Board if he or she wishes to depart from the patient's wishes to refuse treatment.



However, there should always be a bias in support of life and dignity backed by life-sustaining treatment. Accordingly, the onus should be placed on those who wish to refuse treatment, and they should be required to apply to the board for any departure from necessary treatment. The "best interests" principle in section 19 should include an onus in support of treatment. Support of treatment should be the standard, and those who wish to withdraw treatment would then have a responsibility to establish that treatment should be withdrawn. So it should be the reverse of the situation.

Our concern about this arises from documented cases in the US such as the famous Nancy Cruzon case, where a substitute decision-maker suddenly and conveniently found flimsy evidence to establish the wishes of the patient that food and water be withdrawn because it was supposedly in the best interests. The result, of course, was the death of Nancy Cruzon.

In summary, although one of the objectives of Bill 19 is to better promote the role of the family in the treatment of mentally incapable persons, unfortunately, the proposed legislation has failed to do so in two critical areas. These are a minor child's consent and the participation in application to the Consent and Capacity Board by a family member.

Therefore, our overall criticism of the bill is in regard to the unfettered discretion given to health practitioners. We believe the bill gives far too much credibility to health practitioners' decision-making objectivity in deciding a vulnerable person's capacity. Although health practitioners may achieve the technical and professional skills required by their professional associations, this does not automatically confer upon them moral and/or philosophical insights necessary to deal with the issues before them. Health practitioners, just like everyone else, are subject to their own particular biases. It is very important, therefore, that there be checks and balances in the proposed legislation to curb excesses of the authority accorded to health practitioners. This can only be achieved by providing the family with a decision-making role. Without this provision, the bill fails in one of its major objectives.

Now I'll repeat the recommendations:

- (1) The age of consent for minors should be set at 16 years of age.
- (2) Families are to participate as a right in all applications to the Consent and Capacity Board, not just at the discretion of the board or the health care practitioner.
- (3) When a "partner's" substitute consent is given, there should be a requirement that the incapable person's family be notified and consulted.
- (4) The "best interests" of an incapable person should include a presumption in support of treatment and an application to the Consent and Capacity Board should be required before any withdrawal of treatment occurs.

**The Chair:** Thank you very much. Each caucus has only one minute left. Mrs Johns.

**Mrs Johns:** I just wanted to talk about the age, and I know we don't have much time. The Hospital for Sick Children was in last week to talk to us and basically said they believed children were on a scale that changed as

they aged, ie, that they were able to make more decisions as their age grew and their understanding grew.

The health practitioner at this particular point has to look at a child or anybody and decide if they are able to understand the treatment and also, on top of that, if they are able to see the reasonable, foreseen circumstances if they do or they don't take the treatment.

From that standpoint, when you're talking about families always being involved and the age always being 16, what do we do with kids who live on the street, kids who won't talk to their parents and who badly need treatment? What do we do with those kinds of people who would slip through the cracks under your system?

**Ms Watts:** Well, we make an exception for those—

**The Chair:** I'm sorry, the time is up. Very sorry, ma'am. That's the way it works. We're limited as to time. Mr Ramsay.

**Mr Ramsay:** Again, on age of consent, I just want to say as the father of two grown daughters that I believe kids grow up too quickly today and I wish they didn't. It's such a precious time of life and it's the only one time we have that time of our life and then we're adults. But it does happen, and the reality is that many children, from all walks of life, become sexually active very early.

If I had a daughter who was afraid to come to us and say that this is her situation and maybe afraid to go to a doctor because she suspects she has a sexually transmitted disease, I wouldn't want any impediment in law to be placed before her to go and seek that treatment because she's afraid that it might be reported back to me. And even though I wish the whole situation wasn't there, that maybe is the situation. That's why I support the government on this, that it remain open.

**The Chair:** Thank you, Mr Ramsay. Mr Marchese.

**Mr Marchese:** I understand your concern, of course, around number 3, "When a 'partner's' substitute consent is given, there should be a requirement that the incapable person's family be notified and consulted."

I am one of those who supported the rights for gays and lesbians, and many of them have talked about the problems they have with some of their family members who have rejected who they are. They say, "We'd rather be taken care of by our partners or friends that we have been with for a long time than to be taken care of by parents who obviously rejected who we were and who we are." So they have strong concerns about inviting family members who may be distant now, whom they haven't seen for a long time, making decisions on their behalf, which they worry about.

**Ms Watts:** Well, in all three cases we're assuming that the family is incompetent and doesn't really care about the person involved, and in all three cases the family is put in an inferior position, whereas the family has taken care of this person for many years, and quite often when things fall apart, the person involved comes back to the family and the family has to deal with the negative consequences of the situation if the law does not protect the family interests, and most families are concerned about the interests of their children.

**The Chair:** Thank you for taking the trouble to come today with your presentation. We appreciate it.

1020

## OTTAWA GENERAL HOSPITAL

**The Chair:** Next is Ottawa General Hospital, Ms Davis, vice-president, medical affairs. Welcome.

**Ms Marie-Adèle Davis:** Thank you. Good morning. Although I am here today as the acting vice-president of medical affairs of the Ottawa General Hospital, this presentation has been constructed in consultation with a number of the other hospitals here in the Ottawa area.

Firstly, we would like to congratulate the Ontario government on taking the initiative to change the Consent to Treatment Act and the Advocacy Act. These two laws often left our health care professionals facing needless delays in administering care to patients and being subject to an overbureaucratic and complicated system to protect patients' rights. Please remember that all my remarks today are based on the principle that hospitals want to care for people in as appropriate and timely a manner as possible while completely respecting the rights and the wishes of their patients. It is appreciated that the new Health Care Consent Act has addressed many of the most objectionable parts of the consent-to-treatment legislation, and on the whole we are pleased with the direction it has taken. Given the short time available today, I will, therefore, concentrate my remarks on our concerns with the new act.

**Rights advice:** While we applaud the repealing of the Advocacy Act, we are concerned that there is no mechanism in the Health Care Consent Act to advise patients that they've been found incapable and how they can appeal the finding of incapacity. Further, there is no indication of how an application to the Consent and Capacity Board is to be made and who will represent the patient in this process.

The reality is that individuals who disagree with the health care professional's finding will choose to appeal to the board, and therefore there must be a clear and simple procedure to do so. Perhaps this is to be addressed in the regulations. The staff of institutions would be pleased to assist in streamlining this process to ensure that patients receive care without needless delays. As well, tools to document the finding of incapacity must be available at the provincial level for ongoing treatment decisions and any legal purposes.

**The Consent and Capacity Board:** We continue to feel that the board poses a number of problems for both the health care professionals and patients whom they serve.

Firstly, the new act allows for a board of one person. While we can appreciate that such a format will save money and difficulty in establishing boards, we are worried that a single non-health professional will not be able to fully understand the intricacies and subtleties of incapacity.

Secondly, the new act, while allowing the board to assist families in naming representatives and ensuring that the best interests of patients are protected, continues to allow the patient to object. This assumes that the incapable person will be capable of understanding what a substitute decision-maker representative is and the role of the person. This is not always the case. This section needs review and changes to protect the rights of the patient and the families in making important choices.

Lastly is the fact that the new act does not totally eliminate the potential for delay in providing treatment or admission to a care facility. The time lines in the new act need to be carefully re-examined to see if the time for application to the board can be shortened.

**Substitute decision-makers:** The hierarchy of substitute decision-makers was one of the most positive aspects of the Consent to Treatment Act. It is appreciated that it has been retained and clarified. However, there are three points which we would like to highlight.

First, the validated power of attorney no longer appears in the substitute decision-makers list. While the process to be named a validated power of attorney was found expensive by most families, it was less complicated than guardianship when such a type of substitute decision-maker was needed. Therefore, we encourage that the validation process be reviewed, with an emphasis on lowering the costs of capacity assessment.

The second point in relation to the substitute decision-maker is the use of the public guardian and trustee as a last resort. In the acute care setting, decisions on certain treatment issues are needed in the shortest time possible. Experience to date has proved frustrating to the care-givers when a timely decision is needed. It is also felt that the PGT case managers need further formal training to deal with the more complicated treatment decisions such as withdrawal of treatment. As well, the role of the PGT in the placement of patients must be expedited to ensure speedy access to appropriate long-term placement once this decision is reached.

Finally, in the section on capacity, we question why a health care practitioner who is aware that an incapable person is making an application to the board to have a representative named cannot begin treatment if the person to be named representative is willing, available and there are no objections.

**Treatment and plans of treatment:** The changes to the definition of treatment are welcome, as is the flexibility given with the potential to alter a plan of treatment. There will, however, be questions raised by health care professionals as to what constitutes a significant difference to the nature, expected benefits, material risks and material side-effects of the change in treatment compared to the original treatment. The clauses of the Health Care Consent Act with respect to emergency treatment are clearer and more functional than the Consent to Treatment Act.

**Evaluators:** The role of these individuals in conjunction with the capacity assessors is unclear. What training will evaluators be given to ensure continuity and consistency? Further clarification is needed as to the criteria which will be used by these individuals to judge capacity. As well, it would seem that the role of evaluator would be suited to social workers.

Finally, thought must be given to how assessments and evaluations will be carried out in smaller towns that do not necessarily have the range of health care professionals that a larger town or city might have. Vulnerable individuals are most comfortable in familiar surroundings and this would lead to the fairest evaluations. We often have people brought in from smaller communities to our hospital to have these evaluations done.



**Protection from liability:** The institutions at which health care professionals are employed or have privileges should be given the same protection from liability as its professionals.

**Implementation of the Health Care Consent Act:** Thought and time must be given to allow proper implementation of the new law. Health care professionals and their institutions should be provided with practical guidelines to follow to ensure that the new act is initiated with consistency across Ontario. Time is also needed to educate those who will be using the new law, as this will lead to maximum compliance and protection of patients' rights. Finally, any new forms associated with the Health Care Consent Act must be available before the act is implemented, for educational purposes. This was a major problem for us with the implementation of the consent-to-treatment legislation.

**Education of the public:** If Ontarians are to get the full benefit of the Health Care Consent Act, then there is a tremendous need for public education. There is appropriate emphasis given to advance directives. However, the majority of people are unaware of how to indicate their wishes to make them the most useful for the substitute decision-makers and the health care professionals. Information should be given to citizens that advance directives are most appropriately discussed with a health care professional and one's power of attorney for personal care and do not necessarily need legal input. As well, public information about the rights of people with respect to treatment and placement decisions must be widely available in an understandable format.

**Research:** Although incapable persons may not be capable of consenting to research, they should not be excluded from research which is designed to bring insight into the disease from which they suffer. The decision to consent to research should be made by the substitute decision-maker, using the principles of the Health Care Consent Act.

Thank you for providing me the opportunity to address you today on behalf of some of the local hospitals. We trust that the views of a group of large health care providers will prove helpful.

**The Vice-Chair (Mr Ron Johnson):** Thank you, Ms Davis. We want to move now to some questions. We've got about four minutes per caucus, and we'll start with the Liberal caucus.

**Mrs Caplan:** Thank you very much. It was an excellent presentation, and you've identified a number of issues which we've heard repeatedly, the first one as far as the obligation. I want to be very clear that you support a statement in the statute that would give an obligation to those providers, professionals, who will be deeming a patient incapable of making a treatment decision?

**Ms Davis:** Yes. What we want to stay away from is reading the statement that was there under the Consent to Treatment Act. It was complicated, it was very long, and if they read it verbatim, I'm not sure the patient actually was made aware of their rights. That's what we want to get away from, but they do need to be told.

**Mrs Caplan:** I agree that the Mirandizing of the former legislation was not fostering the kind of communication that would see that a patient truly was given the

opportunity to understand. We know there are some who clearly are comatose and not in a position to understand, but there are a whole lot who I think would benefit.

**1030**

I also think it would foster better communication with the professionals, so we've been arguing that there should be something in the statute that requires the obligation. Would you be comfortable with allowing the professional colleges to establish the guidelines or the protocols for how that would be achieved, where there is a professional college?

**Ms Davis:** Yes, we would be, as long as there is consistency. In an institution such as our own, we have a member of almost every one of the regulated health professions, and then social workers and others who are not yet members, so we need to have a consistent message across our institution.

**Mrs Caplan:** That's a really good point. I also agree with you that social workers should be included, and that while they don't have legislation and a self-governing college, if they're going to be included, you have to have something in the statute.

I'm not sure I agree with the concerns you express around the validated power of attorney, and I wish we had more time to go into that. That concept was seen as confusing, that people just didn't understand, and that where there was a need for guardianship, statutory guardianship is possible. I know these are difficult concepts.

**Ms Davis:** What we did find with the families who chose to go with a validated power of attorney, who felt that a full-time substitute decision-maker was easier and preferable for them, was that having the person assessed by two capacity assessors and then filing that with the public guardian and trustee was less complicated than going the legal route.

**Mrs Boyd:** Thank you very much for your presentation, and it is helpful. I'm very pleased to see again a representation from the health care facilities that the patient must be informed of incapacity. We certainly realize that the experience people have had with the form as it was, was not sufficient. It's good that we have an opportunity to hear that the principle is good but the method wasn't and we need to find a new method.

I have reason to know that your hospital is very careful about explaining treatment to patients and asking for consent for various things, so I really take very seriously the commitment you have to that. My criticism around the research aspect—I wouldn't want to be misunderstood, but I always have concern about research issues and how research issues intersect with treatment issues, particularly knowing that we often don't know about the course of diseases and we often have to find out through research how that goes on. But the thought of doing that with incapable people worries me. We have the particular example in this act of the withdrawal of the prohibition on faradaic stimulation, for example, an issue which involves both research and treatment. I wonder if you'd like to comment on that.

**Ms Davis:** One of our concerns is that for a certain population, they will never be capable to consent to research; for example, the population that comes in from a traumatic accident, and we want to do research in

trauma. Without being able to advance and do that research, we'll never be able to afford the medicine that might help other people who may be injured in an accident. Or with the Alzheimer population, the persons themselves may never regain the capacity to consent to research, but some of the research that might be done will bring further insight for future people who may suffer from that condition.

**Mr Marchese:** I agree with you with respect to the implementation of the Health Care Consent Act, the need to educate those who will be using the new law as a way to lead to maximum compliance and protection of people's rights. I think we make a mistake as governments, all governments, in terms of how we implement those new laws and the time we allow and the education that should be allowed to do that, including the education for the public. We never do that as governments; hopefully, we will learn in time, as people tell us to do that over and over again.

With respect to the Consent and Capacity Board, you say the new act allows for only one board member. You're not the only person saying there should be more than one person doing it, because to leave the decision to one person to make that assessment is a scary thought for the person who is the victim of incapacity. Many people support that view.

With respect to treatment and plans of treatment, you're right, many people are worried about the variation of treatment: What does that mean and what does that imply to patients, and can we entrust the health care person to always do the right thing? Many people are concerned about that.

**Mr Klees:** Thank you very much for your report—very concise and very helpful. I'd just like to make a clarification with regard to your comments about the validated power of attorney. In your proposal, you rightfully say that the validation process under the SDA was a very expensive one. I want to assure you, though, that the power of attorney is still there and is ranked second, as it was under the SDA. The only difference is that we're not calling it a validated power of attorney, but it has the same function. We've simply removed the validation requirement, which will streamline the process—

**Ms Davis:** I understand there were the two types of power of attorney under the consent to treatment law, both the validated power of attorney and the power of attorney. I was speaking of the validated power of attorney in those cases where people have been found to be permanently incapable and therefore need a permanent substitute decision-maker, as opposed to the power of attorney which comes into effect once a person becomes incapable and then would go out of effect once that person regains capacity.

**Mr Klees:** Okay. I think our intent with regard to the power of attorney is that it would have the same effect as the previous validated power of attorney, without the necessary requirement for the expensive validation process.

**Mrs Johns:** I just want to draw your attention to—you're talking about the Consent and Capacity Board. The reason we're doing it is the timing factor. I don't know if you were here earlier when we talked about it.

I'd also draw your attention to 71(2)(c), which says these people have to have experience that in the opinion of the chair is relevant to adjudicating capacity. So we're not talking about a person who has never been involved in the process before. They have to be a lawyer; they have to have been involved in the process before; they have to have been on the board for two years. There's some substantial requirements for this person; it's not a person we drag off the street.

**Ms Davis:** I understand that, but what we have found, albeit in just about a year of the implementation of the Consent to Treatment Act, is that almost every one of our boards has been different. There have been different issues, different subtleties around, and it's not necessarily only the psychiatric population but the population made incapable because of disease or age. We feel that the experience and judgement of a health care practitioner might be important on those boards.

**The Vice-Chair:** Ms Davis, on behalf of the committee, I thank you for your presentation.

**Mrs Johns:** Can I make a point of clarification while the next person is coming up? Mrs Caplan talked about social workers. I think she knows—I just want to make sure—that they haven't been set up as a college yet, so we can't include them in that section. But if they were to be made a college, the last subsection in that section says we could set up a regulation that would allow us to put them into that section.

**Mrs Caplan:** However, if in the statute you have a statement that obliges all providers to communicate finding of incapacity and inform them of their right of appeal, if social workers are in that category it would be automatic; you wouldn't have to worry about doing it by reg. That would cover everybody. The other thing is that they're doing it now—we can discuss this further in clause-by-clause—so you've got to find some vehicle, outside of waiting for legislation, to allow them to continue doing what they're already doing.

**The Vice-Chair:** We're going to have to stop you there and proceed with the next presentation.

#### CENTRETOWN COMMUNITY HEALTH CENTRE SUPPORT GROUP

**The Vice-Chair:** We now have the Centretown Community Health Centre.

**Wilderness:** My name is Wilderness. I'm one of the survivors of abuse, so I am part of the vulnerable population, but I'm here on behalf of a group of users of mental health services, family members and friends of users of mental health services. We met through a program at Centretown Community Health Centre. For two years or more, we have been following closely provincial government proposals and policies that affect the mental health system and the people in our community who use it. Some of us are on the district health council mental health board. Many of us are involved with other consumer, family and community groups, as well as being survivors ourselves.

We are all angry and very frustrated with this government's decision to repeal the Advocacy Act. We want you to know that getting rid of the Advocacy Act is not



hurting the NDP; it is hurting the voters who asked for it. The Advocacy Act did not come from a political party. It came from the people.

1040

After many years of consultation, we finally got government support for advocacy, and now the new government is starting the process all over again. We are tired of having to start from point zero, tired of having to educate yet another bunch of politicians. The government should be continuing what the people asked for.

This government is concerned with cutting government spending, so why spend more money on having another consultation on something that voters have already asked for? If, on the other hand, you are serious about doing something about advocacy, why do you need to consult us again? There's already a lot of material from the consultation on advocacy that happened during the last government's term of office that's available for your information. This group sees this as another way of wasting taxpayers' dollars by unnecessary repetition.

Advocacy is a basic thing. It's a lot easier to make a decision to trash the act when you're not the one who has to live with it, but I'm the one who's going to have to live with the decision you make. A lot of people in this community are the ones who are going to have to live with the decision you make. It might be a lot easier for you to make that decision because you're not the one who's in the vulnerable situation.

This government is putting a lot more people in a vulnerable situation and making vulnerable people a lot more vulnerable than any other government has done before. We definitely need the Advocacy Act a lot more than we ever needed it. This is something the voters and people have been requesting for at least 15 to 20 years. We're still waiting for a long time to have this, and just when we're finally starting to have it, it's being taken away.

From an economic point of view, as a survivor myself and in the group as well, we have not found it economical to not provide our rights. When our rights are not being respected, that causes a lot more stress, and when we are much more stressed it makes it even harder to work, so we end up on welfare or disability, and taxpayers have to spend a lot more money that way. Also, we end up with more medical problems as a result of the increased stress from not having our rights respected. It's very tough to try to fight to have these rights respected—very, very tough. I'm doing it myself, and a lot of members in this group are doing it themselves and finding it very tough. It's more money, because we end up being on disability for a lot longer than we need to.

There's an example of a mother. One of the members is a mother of someone who has been in and out of crisis for 20 years. This mother has been unable to work. Every time she tried to work, her child's crisis interrupted. Eventually, she felt she was too unreliable, that it was not reasonable to expect employers to put up with her sudden departures and emergency calls, so she stopped trying to work and she probably got on welfare or something. As she got older, it became harder for her to find work when she did try, so she has been an economically unproductive member of society for 20 years.

This woman feels that if her child had had the support of an advocate she, the mother, would not have been alone in the role of support of her child. The mother's life would have been much more stable and she could have continued to work. It's much more expensive not to provide advocacy support because then people can't work for a much longer time.

It's not unusual for survivors of a dysfunctional family and an abusive family to find themselves in a situation where the family tries to get you declared incompetent just as an extension of the abuse.

There's somebody in the group who said she was depressed to the point that she didn't care about anything, so she signed a consent-to-treatment form. She thought it was part of entrance information about hospitals. They did not mention anything about what the forms were. They did not explain what it was and the next day they came to give her electroshock. She didn't want it, but nobody had explained to her that she had the right to say, "I didn't know what I was signing." They asked her to sign that when she was at her most vulnerable time, which is not a good time to ask somebody to make decisions, usually. They did not explain to her what she was signing either. Fortunately, she had somebody she could phone to get advice, but that meant a long-distance call. But not everybody has someone they can call who can be impartial to help them make the right decision for themselves. She was able to get out of it, but it was a close call. Had it been explained to her what she was signing, she would have refused.

There are a lot of people who have clearly resisted electroshock and were forced to take it anyway. When you're vulnerable, it's hard to make decisions, so you need to have somebody, an impartial advocate, who can be there to help make sure that the form is explained correctly and in a way that you can understand.

**Mr Harry Drury:** Hello. I'm Harry Drury. Traditionally, the court system is a place where vulnerable people have been dealt with. Courts are for deciding what is good and what is bad, who's right, who's wrong, who will win and who will lose. The adversarial relationship doesn't have anything to do with people in the community needing help. It seems to me that it's sort of the white hats and the black hats, the old TV, the old movie stuff; when there's somebody who cannot express what their situation is, the courts traditionally have been there to try to help, but that is not their fundamental function, it seems to me. Advocates are knowledgeable people who can bridge the gap between people needing help in the huge system. They can say: "What do you want? Can we negotiate? Can we figure something out?" They can try to find a solution that both parties can live with instead of a win-lose situation. Advocacy makes more sense.

Here's a story from one of our members. That's me—Harry. I fell down and hurt my shoulder. I was all strapped up. It was mid-February and there was lots of ice around. I had to go to pick up my disability cheque. This was before the computerized deposit system. It was reasonably difficult and dangerous. The somewhat disinterested staff didn't understand why I couldn't get there, since both my legs worked just fine. They would not modify the way they did things just for a month.

Their attitude was: "It's here. Come and get it. Give us proof. Don't give us the truth. We didn't do anything wrong. You are just paranoid."

I'd like to just pick up on that proof thing. How do you get it across to people, when you don't particularly have anything to show, that you're just saying the truth, trying to cope against this whole notion of, "Oh, we've got somebody else here who's bending the truth and trying to rip off the system somehow"? It's a real issue for me. I don't have the proof.

1050

My experience has been that if someone with an official title or an authoritative manner calls on my behalf when I'm in this kind of situation, they get what I need. That's why we need advocacy. This touches on the whole communication situation. People you run across, some of these stories, they're not really able to get the situation across, telling anybody, and in this kind of a situation I'll say it's somewhat intimidating. Somehow I'm able to put myself in front of a group of people and try to get something out. It is very puzzling to me that the whole notion of—boy, time sure goes by, doesn't it? I guess I should wind things up.

To have someone just step forward, rather than going through the whole court system and the official people and experts and one thing and another which traditionally has made sense and I guess is my bias—here we are in the mid-1990s somewhere and things have changed. Things have changed and the old way maybe should be modified.

I think that's about what I have to say.

**Mr Marchese:** We want to thank you for your presentation. It's people like yourselves we need to hear from when we talk about the changes that have been made here. One of the things that people have talked about is the retaining of the Advocacy Act. What both of you talked about is the need to have people who are there, advocates there to support you, rights advisers who are there to support you, because it's very difficult on your own at times to be able to deal with problems or solve problems. In getting rid of these people, the rights advisers and the Advocacy Commission, who helped people like yourselves, you'll find more and more people alone again out there, trying to cope and trying to deal with difficult personal problems. We thank you for your presentation because we need to hear those things, and I think the government members particularly need to hear the concerns you've raised.

**Wilderness:** The main problem I have is being revictimized and having my rights not respected. That's the number one problem I have.

**Mrs Boyd:** I'd like to thank you as well. You've told a number of stories, some your own and some of those in your group. I think one of the points that you made was the frequency with which people who are survivors in fact are survivors of abuse within the family, and therefore the need they have for advocacy outside the family. While that is not something the general public wants to hear—we'd like to believe that all families are supportive and caring—the reality for people like you is that that's not the case. It's important for us to hear in your own words that this is not the case again and again.

**Mr Klees:** Thank you very much for your presentation—very much appreciated. I'd like to take this opportunity to clarify something for you. I want you to be assured that the repeal of the Advocacy Act does not mean the repeal of advocacy in the province. What it means is that we're going to be doing away with a commission and with a system that would cost \$18 million a year. I think those you represent understand that's a lot of money that we can't afford to simply continue to put into a bureaucracy. What we want to do is ensure that your rights are protected, that you have the kind of support you deserve, but we want to do it in an efficient way so that we can provide more people with advocacy support in this province. That's our commitment to you and that's what we're going to achieve here.

**Wilderness:** Traditionally, I have found that it's more expensive not to provide advocacy because then I end up—I could be back in school right now if it wasn't for all the time that my rights were not respected and all the fight I have to put up. But I can't work and I can't go back to school as a result of that, so it becomes more expensive to taxpayers not to provide advocacy.

**Mr Klees:** We do intend to provide advocacy. We just don't believe it's appropriate to provide it in the expensive way that the previous act was providing it. I want to give you that assurance.

**Mr Clement:** I wanted to take a different tack and say, in the 30 seconds I do have—Ms Boyd talked about survivors of family abuse, but there are survivors as well of institutional abuse. Institutions wreck people's lives. Governments wreck people's lives. We, on this side, from a moral perspective, don't see more government advocates, more government inspectors necessarily being the solution. That can add to the problems rather than subtract from the problems. We want friends and family who care about and love the vulnerable person to have more of a say. That's where we're coming from.

**Wilderness:** I want the survivors to be the ones who decide for themselves.

**Mr Clement:** Quite right.

**Mrs Caplan:** If the government means the words that we're hearing, I'm hopeful that it will accept some amendments to this legislation. It's clear that they're planning to scrap the Advocacy Act. They're not going to go back on that, but I believe there are some changes that could be made under the existing legislation, the remaining consent to treatment and the substitute decision legislation, that could put in place some of those safeguards—not all, but some. For example, if there is a statutory obligation of providers to inform people when they have been found incapable, I think that is one protection. It would also be a requirement to inform them of their right to appeal. That's something that's missing from this.

But there's another one, and I hope the government will listen, because this is a response to your concern. The Psychiatric Patient Advocate Office has a very good reputation. They, right now, only have a mandate in the provincial psychiatric hospitals. Rather than allowing a hospital administrator to appoint an advocate who might be a chaplain, as proposed by Mrs Johns, I would be far more comfortable, and I think many in your community



would be more comfortable—this is my question: Would you be more comfortable if this act specified an increase in the mandate for the provincial psychiatric advocacy office to include all of the community hospitals that provide psychiatric programs as well as community-based programs where there may be a need for an advocate from time to time, or someone to offer assistance, as they have been doing in psychiatric hospitals?

**Wilderness:** I think what we would be more comfortable with is that advocates would really be impartial to hospitals and not connected with professionals and also be survivors themselves.

**Mrs Caplan:** That's the experience of the PPAO. They are independent and they're impartial and I know they are well respected by the people they have been serving in the provincial hospitals. It's not a perfect solution, but it's an alternative.

The other proposal: Right now this legislation talks about psychiatric facilities. I'm going to propose an amendment that will change the word "facility" to "program," because it's not the bricks and mortar. There are many community-based programs, and that's the whole thrust in community mental health. That change would also ensure people's rights whether they were in a facility or in a program, and I think that's the sort of thing you want.

1100

**Wilderness:** Not all survivors are dealing with hospitals and stuff. Like, I'm trying to heal my childhood abuse for many years now. I'm trying to do that without having to be sucked into psychiatry, because I don't have a mental illness; I just simply have been abused. So I shouldn't have to deal with hospitals. I do need support, but outside of that. I'm finding it extremely difficult to be able to do that; in fact, almost impossible, because I'm not having the support that I need to do that outside of it.

A lot of the times when my rights are not being respected is within the government. Like compensation for victims of crime, I'm having problems with that. In regard to having counselling that's not psychiatrically related, like a social worker, it's not covered. So those kinds of things are also a problem. There's revictimization outside of psychiatry as well. So this is another concern that I have, that it be broad enough to cover anything, anywhere where your rights are not being respected.

**Mrs Caplan:** I'm not sure you're going to accomplish that, but thank you for an excellent presentation.

**The Chair:** Thank you for your presentation and assisting the committee today.

KENNETH SMITH

**The Chair:** Mr Kenneth Smith, the Lanark County Law Association.

**Mr Kenneth Smith:** I expect to be fairly brief. I appreciate the opportunity to appear before the committee. I come as a lawyer who has been in private practice in the town of Perth for 17 years. I'm a member of the Canadian Bar Association and of the Lanark County Law Association. I think, having canvassed my local colleagues, the views that I will be expressing in this

presentation fairly well represent those of my profession, at least in the local area of Lanark county.

I'm going to confine my remarks to the Advocacy Act, the repeal of that act and to the amendments to the Substitute Decisions Act. Certainly, I find most welcome the promised repeal of the Advocacy Act. I believe it created a new level of bureaucracy in the person of the Advocacy Commission, and it seems to me that the commission was highly intrusive into the lives and financial and property affairs of people in a most extensive fashion, all in the name of protecting vulnerable persons.

I was most especially disturbed that the act required that in each and every instance where a person was certified incompetent pursuant to a properly conducted assessment, an advocate would have to immediately be dispatched. That advocate would have to meet promptly with the individual so assessed to counsel that person to the effect that he or she did not have to abide by the power of attorney arrangements that they had made perhaps some years earlier when competent to do so. It has always seemed to me quite unimaginable that a government bureaucrat should be counselling a person assessed by two assessors as incompetent to try to proceed to undo arrangements that they had put into place when they had been competent to do so.

This situation applied both to powers of attorney for property and those for personal care. In each case where an advocate intruded, it would be necessary for the attorney named in the document to make a court application to be appointed either guardian of property or of the person. The result of this process is a significant expenditure of both time and money, all as a result, I believe, of a legislative provision whereby a government bureaucrat would encourage an incompetent person to undo arrangements that they had earlier made.

So I respectfully submit to the members of this committee that the Advocacy Act would have been highly intrusive, resulting unnecessarily in complications and expenditures of time and money. I believe it was an ill-conceived legislative endeavour, and I believe its repeal by Bill 19 is to be applauded.

As to the Substitute Decisions Act, I am certainly pleased that the amendments proposed by Bill 19 make it clear that the public guardian and trustee is only to be involved as a very last resort. Under the present legislation as it now stands, when a certificate of incompetency is issued, the public guardian and trustee automatically becomes statutory guardian of that incompetent person, despite the fact that a power of attorney had previously been signed and had not been revoked. The person named in the power of attorney would then have to apply to displace the public guardian and trustee as the individual's guardian of property. So the public guardian and trustee was, I believe, in the existing legislation put in the intrusive position of deciding whether the power of attorney arrangements made by the individual, when competent, should in fact be allowed to be implemented.

Just as in the advocacy provisions mentioned earlier, I believe this to be a matter of government setting up a system to judge whether or not arrangements effected by a person, when competent, are in fact in that person's best interests. I cannot accept, and I do not think the



average person in Ontario accepts, that the province knows better what is best for the individual. I believe the provisions of Bill 19 as proposed effectively redress these problems in the existing legislation.

There are, I believe, some areas where the thrust of Bill 19 could perhaps be more effective. By virtue of section 32 of the existing act, it is the duty of a guardian of property to consult "supportive family members and friends" of the incapable person in the decision-making process. I believe this presumes far too much about family relationships, which in some instances can be strained. For example, a person might have several children and might have complete confidence in two of those children while perhaps others have problem characteristics. Accordingly, the parent executes a power of attorney in favour of those two individuals, those two children whom they trust implicitly. Those two children might be very greatly hampered in carrying out their duties as attorney for property if they have to consult with the others, who may be wayward or have characteristics making it inappropriate to consult.

So I believe perhaps you have once again a situation where the legislation could be improved by considering the removal of the consultation requirements of section 32 or, alternatively, the addition of a provision to the legislation whereby a person can include in their power of attorney a clause removing the duties of consultation.

I am concerned that Bill 19 appears to propose to remove the requirement of an affidavit of subscribing witnesses attesting to the belief that the grantor is not incapable of giving a power of attorney. I do have concerns about that. There will undoubtedly be instances where an interested party will attempt to have a power of attorney set aside on the ground that the grantor was not capable when it was executed. I believe in these cases the affidavit of subscribing witnesses mentioned above can be very important in upholding the integrity of the document.

To remove the requirement of the affidavit would result, I believe, in a greater degree of costly litigation in the days to come, as the non-presence of the affidavit will have the effect of making the power of attorney document a far more assailable target for those who would attack it for whatever reason. So I would urge that the affidavit of subscribing witnesses attesting to the person's capacity at the time of execution be retained.

One other possible problem area I wanted to point out is that under the present legislation, when a person gives a continuing general power of attorney, or any power of attorney, it all automatically revokes any previous documents in place. A problem could conceivably arise where a person had signed a continuing general power of attorney for property and finance and perhaps several years later, forgetting about that document, is going away for a time and signs a specific power of attorney in favour of another individual to complete a business transaction, perhaps to handle a bank account or pay bills at the bank. In such a case, the general power of attorney for property previously given is automatically revoked, when clearly it would not be the intention to do so in signing the specific document that I mentioned. So in view of these circumstances, I think Bill 19 could be perhaps improved by containing a provision whereby it is only a general

power of attorney that can revoke a general power of attorney.

**1110**

I'll make one final comment. I had the opportunity in April 1995 to make a presentation in conjunction with your colleague, Leo Jordan, on the legislation as it was then. During the course of that talk to the audience, I mentioned that a person had only to be 16 years of age in order to be a power of attorney for personal care. I remember the audience gasped in unison at that time and there seemed to be certainly a strong feeling that 16 was just too young for this sort of responsibility. I don't believe the new bill has raised that age but certainly that's a consideration that I would recommend to the committee. I thank you.

**Mr Klees:** Mr Smith, thank you very much for your presentation. I'd like to just draw your attention to comments that you made on page 3 with regard to the affidavit of the subscribing witness. I think your statement here implies that Bill 19 proposes to remove the requirement of the affidavit of subscribing witness.

**Mr Smith:** I believe so, sir.

**Mr Klees:** I'd just like to clarify for you that the SDA did not have a provision for an affidavit of subscribing witness, neither did the previous power of attorney act, so this is not a change. I think what's very important—one of the reasons that we're even here—is that the complexity of the process under the previous legislation was such that people were very confused and they found it cumbersome. What I think this would mean is that they would have to come to you as a lawyer in order to put a power of attorney in place. Is that not true? Would that not then add to the cost as well as the complexity?

**Mr Smith:** Not necessarily. No, not necessarily at all. A person could have that affidavit commissioned—the witnesses could have their affidavit commissioned in front of a municipal officer or some other such person.

**Mr Klees:** But it would add that additional step—

**Mr Smith:** It would add an additional step, but I think perhaps in the long run it might be a good step to be able to hold the integrity of the document, should it be questioned at some future time. You have a sworn affidavit there on the part of the witnesses. I think it could be quite helpful.

**Mr Klees:** Okay. I did want to clarify that it is not a change, it's not something we're removing at this point.

**Mr Smith:** The form is presently in use; certainly the forms that are widely in use are including this affidavit of subscribing witness.

**Mr Duncan:** First of all, thank you for a very thoughtful presentation. In terms of section 32, page 3 of your document, and removing the consultation provisions in section 32 or the addition of a provision whereby a person can include in their power of attorney a clause removing the duties of consultation, it's premised on a notion that's been of some concern to us and that is whether or not a family member or members, or certain subsection of family members, will act in the best interests of an individual. Can you elaborate more on that and share some of your experiences in that area with us?

**Mr Smith:** Generally I find when an individual wants a power of attorney and designates a particular child, say



one child out of two or three, they're doing so because they want that particular child, for whatever reason, to be the one to make decisions on their behalf. Presumably they're closer to that particular child, or friend, if not a child, and they have confidence that that person will make decisions that are the decisions they themselves would have made had they been able to do so.

To require that person in whom confidence is espoused then to have to go and consult with others in the family I think is counterproductive and perhaps contrary to the wishes of the individual who signed the power of attorney in the first place. They gave it to that person for a purpose, they didn't give it to all three, if they have three children, they gave it to the one. So the presumption, I think, should be that that person should proceed without the obligation of consultation.

**Mrs Boyd:** Thank you for your presentation. While we certainly agree with you that many of the processes that were set up under the previous acts may have been cumbersome, I certainly can't agree with your belief that the Advocacy Act or advocacy is not important. Listening to the people who have come before us and the importance of advocacy for vulnerable people, I simply can't agree with your premise that advocacy necessarily means that government somehow is trying to take over from individuals. In fact, what it was doing was trying to support individuals in being independent.

Some of your concerns that you've described around the Substitute Decisions Act, I agree with. You're concerned about section 32. It's a real concern for me as well because it does make assumptions that consultation is not going to give rise then to challenges as to whether or not the power of attorney was appropriate in the first place. Very often, those very family members who the person does not want making decisions on their behalf want to force decisions according to their values and principles as opposed to the individual's, and certainly at end-of-life decisions, that might be a particular concern, so I wanted to say that.

On the age thing, that's been a real issue and it's been discussed a lot, but the age decision was made, 16 being the age at which children are independent of their parents, on the request of a number of people. Where there is only a child and a parent and that is the only family there is, it would have made it impossible for that child to have some say in terms of what happens to a parent who is ill. There were many representations made to us about those kinds of situations.

**The Chair:** Thank you very much, Mr Smith, for your presentation.

**Mr Klees:** Mr Chair, I have a point of clarification. I think it would help the members of the committee. It's with regard to the concern raised by Mr Smith about consultation. It's important to clarify that the consultation is with supportive family members. That would perhaps address, Mr Smith, your concern about family members who may not be supportive of a particular direction.

**Mr Smith:** I appreciate that. I'm aware that the wording is "supportive family members and friends." I guess at that point anyone who is a family member can be claiming to be supportive when perhaps they're not. There's just a degree of interpretation in there. I do

believe that Bill 19 is excellent legislation. I just feel that there are some improvements, perhaps, that could be made in those very specific areas.

MARIANNE TAYLOR

**The Chair:** Our next submission is Ms Marianne Taylor.

**Mrs Marianne Taylor:** Thank you; that's Mrs.

**The Chair:** I tend to use the word "Ms."

**Mrs Taylor:** I realize it's politically correct.

**The Chair:** That's correct.

**Mrs Taylor:** I'm old enough to affiliate it with other things.

My name is Marianne Taylor and I'm an advocate. For the last 15 years I have been paid by the province of Ontario to provide advocacy services to people you now refer to as vulnerable persons. I have worked under the auspices of the Renfrew County and District Health Unit. The name of the program in which I provided advocacy services was the adult protective service program. I regret using the past tense. It is the adult protective service program, which you have come to know under the term APS.

During my tenure of employment with the health unit, I was elected to represent the needs and interests of the regulated health care practitioners who work within the health care environment of the community. This afforded my knowledge of what the requirements of the regulations of working under a college and providing health care can bring for these individuals.

In March 1995, I undertook a one-year leave of absence from the Renfrew County and District Health Unit to act as a rights adviser for the Ontario Advocacy Commission. To the best of my knowledge, I don't think there is anybody else who has had a combination of this tenure and experience in delivering advocacy services in the province.

1120

I'm not going to try and address the specifics of Bill 19 because I think you'll hear enough of that. I'm going to try and address the impression of advocacy and my opinion of some of the issues which have arisen under a lot of different legislation. Some of you may or may not realize that Bill 188, which I believe arose in 1973, was really the first attempt to codify living wills and informed consent.

This small card, which has a picture of me from many years ago, was that which I used to enter the homes, to enter facilities, and to assure people of my credibility as an advocate who would be accountable under the parameters of the province of Ontario when I delivered services.

This card is my licence as a rights adviser. It serves the same function. It assures people that I operate and will deliver services in an accountable manner under the legislation at hand. It tells people when I walk into their home that if I misbehave or really tick them off, they've got somebody to call and they've got somebody who will deal with me.

It is important for you to know that my ability to continue being employed does not rest in Bill 19. If you abolish the commission, if you abolish independent and

impartial rights advice, come April 1, I will be back to providing advocacy services to the people of Renfrew county. I feel they will be greatly advantaged by the fact that I have the knowledge, the training and the experience of having been a rights adviser.

I would also like you to know that today I'm speaking to you as an individual. The people, the groups and the employers which I have referenced will each be making or have made their own presentations and they will represent the collective view. I feel strongly enough about this issue to come forward today, unpaid by the commission and away from my duties, to address these issues.

I would also like you to know that I have just learned that the Clemens coroner's inquest has, through recommendation 31, just recommended that independent and impartial rights advice be continued for vulnerable persons under consent to treatment or what we now know as the Health Care Consent Act.

I think the greatest single dilemma with what I call the partnered legislation of the Advocacy Act, Consent to Treatment Act, consent and capacity statute law amendment—I've never quite straightened out which comes first, amendment or law. The whole problem with those acts was the fact that they were so grossly misrepresented and poorly marketed in the community.

As an adult protective service advocate who had, since the early 1980s, been committed to independent advocacy and working with the government, vulnerable persons and their families in moving towards independent advocacy systems, I did not have a clue what this legislation was about. I was privy to going to private meetings, to Ministry of Health meetings, to advocacy meetings, Comsoc meetings. I had access that the general public just didn't have, and prior to undertaking the licensing requirements which were provided by the commission, I really had no idea what was going on. I was very angry. If I didn't know what was going on, I was fairly certain that the people I served really didn't know what was going on.

After taking a very lengthy period of time of study and passing examinations, examinations which several of my colleagues did not pass and therefore were not able to provide rights advice or rights information, I become very committed at understanding what this was about. It's just that we weren't allowed to interpret for people. That was unfortunate in some ways because we constantly had doctors and so on asking us: "What does this mean? What should I do?" We'd have to direct them back to their college or the Ministry of Health.

Misinformation was one of the largest problems in this whole legislation, and in that respect, I believe the Bill 19 response is a response to perception and not a response to the reality of how this legislation could have worked.

By suggesting that people—you tell somebody something, that it's going to cause them to do something that's not good, that's very protective, and it's not, I don't think, where Ontario wants to be. Do we really want to be deciding what each and every citizen should know? I think that's far more consistent with a Marxist agenda than it is with the agenda we now see coming from the government. Citizens, even in incapacity, have the right to know what's going on. They have the right to ask for a review.

Review: the one word taken out of the mandate of the Consent and Capacity Board. I don't know why. I hope that at some point the government will address this. It's kind of like when they took "fair" out of the Employment Standards Act. Don't know why, but maybe there's a reason for it.

The partnered legislation was fragmented. My biggest frustration, and that which I have heard from the more than 400 people I have seen in the course of rights advice in the city of Ottawa, and the county of Renfrew, the county of Lanark etc—because this is a huge area—has been, "There's no one person I can telephone." If I want to know about substitute decision-making under the Health Care Consent Act, I've got at least three phone calls to make, one to the Ministry of Health, one to the public guardian and another to the Attorney General, which is a different part of the public guardian.

Citizens have been so frustrated and they've taken it out on, "Well, if you hadn't told that person what was going on, none of this would've happened." Telling them didn't cause this. What caused it was the inability of the system to respond to the needs of families to make this simple, to apply simplicity to this legislation. Going to the review board to seek a decision does not cause difficulties. What it does cause is that you have to trust that you've put the right people at the review board who can make the right legal decisions. So fragmentation needs to be addressed and you've not repaired that in Bill 19.

Advocacy: The Ontario Advocacy Commission never implemented the legislated advocates. I was offered the job, thought I had it, and after the election, "Sorry, we're not implementing it, so you get to stay a rights adviser." Well, thank you, I mean it's been interesting, but I would rather have been an advocate.

Therefore, we've had a gap. The other day I watched a doctor. I had responded to a consent-to-treatment call. I was there within an hour, as we usually are, within an hour or so. If I have to go up to Pembroke, maybe it's going to be three hours, but that's our top priority. We're there. We've never missed. That doctor, after I had served him written notice, which he can put in his file, which says what the decision of the patient is, turned about, he could not find a substitute decision-maker. He was calling the families. I watched him for an hour, because I was seeing other people, and every time I came out he was on to another family member explaining what the situation was, and they were telling him to go away. They don't care. They don't want to have anything to do with it.

Finally, he called the public guardian. The public guardian said, "Hey, if there is a living and breathing family member out there, we can't help you." So the doctor turned into an advocate, came to me for help, and I would never admit to you here today that I ever did that because that's not my function. That doctor could've seen six or seven patients and done his real job rather than doing my job of an advocate.

You've not repaired that in Bill 19. Doctors, nurses, hospitals, facilities and family members will be so frustrated by trying to assume their responsibilities. I have a bit of a nightmare of my sister and I trying to make a decision about my mother, and we're not dysfunctional,



we're just normal people who have different points of view, and if mom ever needs our substitute decision-making, our diverse values and beliefs have no reconciliation in Bill 19.

The lack of training provided to regulated health care practitioners, the public guardian and most people has been a real problem in this. The transition from the current legislation to Bill 19 is going to be a nightmare. I have no problem telling you today that as a rights adviser, I am on legal termination of employment notice from the Ontario Advocacy Commission to take effect on March 29, 1996.

1130

As I understand it, third reading couldn't even begin until March 19. If you believe that 10 days are sufficient, the mayhem that we saw on April 3, 1995, will look like a party compared to what will happen on March 30, 1996.

I believe in advocating for rural communities. I come from Renfrew county. We have no schedule 1 psychiatric facility. We have, however, been forced to live with the substitute decisions and consent to treatment act, which removes our rights and removes our ability to respond to issues of incapacity. We are still kept at home. We still lose our property. We still send our seniors to places where nobody will hear them, and yet we do not make any effort to make sure that the provisions are still in place for that person to have the same access to rights information and advocacy.

In a psychiatric facility at this time, a mandatory referral is made for rights information. What made psychiatric patients so special? Whatever happened to my mother? So if a capacity assessor, which by the way I personally can't afford on the salary you pay me, decides that my mother is not capable of property management, she loses the right to manage that property under Bill 19. Yet, you have done nothing to ensure her right to rights advice under the Health Care Consent Act. People living in the community do not have the same opportunity for rights information and facilitation.

I would suggest that perhaps the government may wish to look at making this a more equitable society and say, "Maybe not just psychiatric patients need rights advice and rights information; my mother and my children may also need it." They'll get it from me, except it really won't be rights advice, because I'll have their best interests at heart, and that's not what rights advice is about.

I do believe that it is important for you to consider looking at having advocacy available to serve the needs of all citizens. Advocacy is a very defined and skilled trade. It is one where emotion does not enter into arguments represented on behalf of vulnerable persons. It is one which respects the integrity and actions of family members. It is a non-intrusive service. I don't know where this came from, just because you can go into a home.

This little card issued to me by the province of Ontario in 1981 gives me the right to enter any facility between dawn and dusk, and any home. This is not new. It's how it's carried out. As a government bringing forth legislation, you I believe have the responsibility to ensure that all citizens of Ontario have the right to those little

anomalies and those very real situations out there which have kept me in business for 15 years. I don't often see overly healthy families. I don't often see overly healthy individuals. I deal with situations of gross abuse, neglect and even where your own laws have served to marginalize an individual.

I might say to you, just going back a bit, one of my real efforts in 1981 was to have the government realize that it's not fair to have family benefits cheques sent just to the man of the house. This was outrageous, just outrageous. People thought this was a bizarre notion. I think we now realize, and it does happen in Comsoc, that the lady of the house may also receive the family benefits cheque if that's the agreement of the couple.

So when we talk about advocacy and we talk about what seems bizarre today, 10 years from now that may be seen as very routine. I know that was a minor example. Usually the situations are more serious than that.

On a final note, I would like to tell you that it is my personal belief that advocacy and advocates are a function of the political right. In the political left, regulations abound. Everybody's regulated. There's really no room for people to move outside of the parameters. In the political right, which is where advocacy did evolve from in the early 1970s, there's an aspiration to get to that ideal family, that ideal situation, that ideal response. But there's the recognition that the advocate is needed for those situations where the ideal is not being met.

**Mrs Caplan:** I think you've put the case very well. I don't think the government is going to not scrap the Advocacy Act as part of Bill 19. So one of the things we've been looking for or some of the things that we could do to amend the bill as it stands now that would leave in place I guess the foundation—you've identified one advocate service that's been around for a long time: the adult protective service.

You mentioned the Psychiatric Patient Advocate Office. They only have a mandate in provincial psychiatric hospitals. So not only do you have two classes of people in the province; you actually have even two classes of mental health patients, and one of our proposals is that the Psychiatric Patient Advocate Office's mandate include all of those who are in a provincial program, as opposed to just a facility.

Would you support that kind of amendment to the legislation, albeit that it doesn't achieve your goal?

**Mrs Taylor:** I realize we're stepping back. Basically, I think we're heading back to 1973 and we'll have to mature and grow again and try and get it right this time. I would support the Psychiatric Patient Advocate Office assuming rights information and advocacy, continuing with that, provided that there were no other options.

I have worked with these people. They were brought in to work with us and I have come to know them; in eastern Ontario, we had a great relationship with our PPAO counterparts in Kingston and Brockville. What we did see very clearly was that there's a totally different set of skills which comes with working in a community environment, in acute general hospitals, working and going into someone's home as opposed to the common environment of one facility. That would have to be dealt with. I

also believe you have community-based advocates through the adult protective service program.

**Mr Marchese:** Just to make a few comments in agreement with what you said and then to ask you some quick questions. First of all, with respect to education of the public, there was another group behind you that also talked about that. I agree strongly that governments almost have an obligation to explain their laws. We also leave that education to the public and to those people who need to administer the law, and often that leads to a great deal of confusion, as you also pointed out. So we have to do that.

The other point you made is, why do psychiatric patients have access to rights advisers and why not the rest of the population? You mentioned your mom. We agree with that. We think rights advisers are a must, and I'm looking forward to seeing what the government will propose. Mr Klees says we've gotten rid of the Advocacy Commission and the act but we will restore advocacy. What that means, we're not sure. I'm not entirely clear about what they might propose. In fact, I'm worried about what they might propose, because we don't know yet and I'm certain it'll be very minimalist, if any.

You point out, with respect to the whole notion of rights advisers, that they're not intrusive. A previous speaker, a lawyer, said he was happy we got rid of rights advisers because it was a whole new bureaucracy whose whole purpose was to intrude on person's lives. You pointed out how that isn't so and how accountable you are for your actions.

Last question: Given that they're going to eliminate the Advocacy Act and the rights advisers, what suggestions do you have to this government about what else they might be able to do?

**Mrs Taylor:** I think the government needs to understand that the elimination of rights advice puts the government at risk. There's going to be a lawsuit. You won't be without rights advisers long, because there will be court actions that will decide you need them. I think the doctors will revolt. The doctors in Ottawa have been very clear with me that they like getting written notice of the decision of the patient. They like the expediency. They like the idea that they are free to do medical work and to meet the best interests and ethical obligations of their work.

Rights advice: I don't have a proposal other than saying that rights advice is necessary. If we're a democracy and we actually believe that all our adult citizens have the right to know about decisions which will remove charter rights of liberty, the management of property and finances and who will do what treatment to my body, then you can't be without rights advice. I don't believe it is the function of any volunteer who has no accountability, and I'll tell you, no volunteer would work in the conditions I've worked in. No volunteer would be able to stand it. You cannot flinch. When you are meeting with a patient and a doctor and the patient strips down, you can't flinch.

1140

**Mr Parker:** Thank you very much for your comments this morning. I was looking over the recommendations that are a few pages into your submissions here. I just

wanted to follow up on recommendation number 5, that the bill "provide for equitable and reasonable access to capacity assessors for all citizens...regardless of community and/or income level." That's a concern to us as well, frankly, and one that we felt needed some attention. With that, we took a few steps towards addressing it in subsection 71(2) of the Health Care Consent Act. That's on page 102.

**Mrs Taylor:** I didn't bring my act with me. Sorry.

**Mr Parker:** Okay. What the proposed bill provides is that in certain cases a single assessor can act alone, and there are particular qualifications that have to apply to that assessor before the assessor can act alone. If you read the qualifications, it reads much like the qualifications for a high court judge. Particular assessors can act alone in that capacity, and that gives some flexibility to the provisions of the bill, so where a remote location is involved, you can get the assessor up there to carry out the assessment. You're not involved in the cumbersome apparatus of a large assessment board with the whole process that would apply in other cases. That's an attempt to give some flexibility to the bill to make access to assessors a little bit more readily than at present. I wonder about your comments on that.

**Mrs Taylor:** I think perhaps some of my point may have been missed. What I'm saying is that as long as you have a set and established rate that must be paid by the citizens of Ontario to exercise their rights, to exercise their options under legislation, you should have a mechanism—some people will say there is one but I know there isn't; I know it's not working—that allows everybody in Ontario, regardless of income, to access a capacity assessor, or to not be disadvantaged by happening to live in Pembroke and the capacity assessor's in Ottawa. You're going to pay four hours' travel time, so your costs go up.

I think what I'm suggesting to you is yes, make the system more user-friendly, but the beginning of that is, let's get rid of the absolute elitism of the Substitute Decisions Act. It is so elitist that it is only available to people with the money and the knowledge to exercise the options under it. The rest of us are going to have to go hightailing to the psychiatric facilities in order to get the doctors to do exactly the same thing.

**The Chair:** Thank you, Mrs Taylor, for sharing your concerns with the committee today.

#### BILL CARNE

**The Chair:** Mr Bill Carne. Welcome. You have 20 minutes, including questions, and you have the floor.

**Mr Bill Carne:** Thank you very much. I'm not doing too well this morning. I recognize that the government didn't like advocacy, and it was my intent to go back to what I call my year of hell just to show you why rights advisers are required. My problem is, I am reliving that and it's hard to talk coherently at times.

This morning I wrote some of these thoughts. I've been thinking what to say to this committee for the last month. It's been the only thing I've done since Friday evening. As I mentioned, I had a great deal of difficulty focusing on it and I could not figure out why until recently.



I know the government wants to repeal the act. I don't believe it would be wise. It would be very costly in human terms, and to me, even more importantly, it's more costly because it helps maintain what I see as being an inefficient institutional mental health system.

By the way, I should say that I call myself a professional crazy person. Sorry, I'll do that later. That shows you how incoherent I am right now. Anyway, I'm reliving my year of hell. I'm reliving the pain, the panic and despair that I was then experiencing.

In the formal part of my presentation, I had planned to refer to research showing that the most productive thing in helping us when we're in trouble is "somebody who believes in me." But the stigma of having a mental illness is so great in our culture that things can happen to us with the tacit approval of our society that would be considered to be an outrage if it happened to ordinary citizens.

That's where the Ontario Advocacy Commission came into our lives. I have trouble when I say these words. Finally, there was someone out there who believed in us. There was a lot of positive therapy in knowing that, even if we never used their services. The only reason why I'm able to talk to you today is because somebody believed in me. I had a very supportive GP.

Anyway, the more formal part is, my name is Bill Carne. I've been acting as an advocate for people who have used mental health services for the last five years. I'm the member of a board of directors of two groups of consumer/survivors in Ottawa. I'm a member of the Friends of Schizophrenics families group, as well as the self-help group of those diagnosed with schizophrenia. Because of the mental health reform process I am at the table with all kinds of professionals and to achieve equal status I now refer to myself as being a professional crazy person. As proof of my insanity, I would far rather attend a committee than go to a movie.

But I'm quite lucky, it's not under the DSM IV. I forgot my props here. This is the big book that decides whether or not you're crazy. So I'm not crazy for that apparently.

I'm one of the lucky people who are crazy. I was educated, had a career and then things happened to me. As a result, I've got a degree in physics, which taught me to determine why an event is taking place. I have a masters degree in electrical engineering which taught me how to go from a known existing situation to achieve a given objective and then I got sidetracked and got a degree in social work—I think I was my most primary client—in community development and that taught me how to ensure the human element is included in achieving any objective.

I've been diagnosed with nine different kinds of craziness. I do agree with schizophrenia and major depression and dissociation, which is a mild form of multiple personality disorder.

In summary, I've a very unique way of looking at the world. I recognize you get lunch after I talk and I was hoping to offer you some food for thought, and I hope I still can.

I think I should say, though, the views expressed are mine and not necessarily those of the groups that I belong

to. Most of my comments apply to those who have a psychiatric disability. I recognize that for those who do not have the ability to make decisions for themselves, as say in severe cases of Alzheimer's, the rights advice process is probably a waste of time. But since, as I will show later, there's no accurate means of determining competency, easy access to a formal review board hearing is needed in order to be fair to disabled people when they're vulnerable. This is especially true for the situation of people with a psychiatric disability because their competency varies widely with time.

I think it's important to recognize that when you use the words "mental illness," every person you would talk to has a different impression of what it is. Part of that is because the diversity among people who are diagnosed with mental illness is extremely great. There are those where the illness comes on early and, as I mentioned, there are those who were educated, had careers and then something happened. There are those who believe they've been well helped by the mental health system and there are those who believe they've been so abused by it, they want to abolish it. There are those whose condition is mild and there are those who were in so much pain that they chose death as a way to end the pain.

**1150**

I think it's important for the members of this committee to understand what happens to a person when they're declared to be mentally incompetent. If you talk to a psychiatrist, it is something very positive and valid. What is left unsaid is that it's a form of incarceration where more basic civil liberties are lost than a criminal loses in prison. In some ways, it's worse than being a criminal. A criminal is not locked up for something they did until after the trial. A psychiatric patient can be locked up, based upon the opinion of a psychiatrist, for what they might do in the future. There's a great difference.

That leads to one of my main issues. In general, it is impossible to accurately predict people's future behaviour. But that is what a psychiatrist is asked to do when they determine mental incompetency.

There is no way of predicting which stressors and supports a person might encounter in the future. Behaviour that indicates irrationality in one person can also be behaviour carried out by a stable person and we get judged by our behaviour, and not by what we're thinking and feeling.

For normal people fines for speeding would not be permitted unless radar was 100% accurate; the same is true for giving fines or suspending drivers' licences after a breathalyser test is given. If they're not 100% accurate, it would never be allowed in our society.

I gave a talk to the Ontario Psychiatric Association about a week ago about stigma as part of a panel and recognized from my comments and the panelists' comments and questions from the audience just how much stigma affects our lives and how again things that wouldn't be acceptable for normal people are considered to be quite rational for us.

So because of the stigma of mental illness in this country, its citizens are willing to have us locked up based upon the opinion of what someone thinks we might do in the future. If I were better prepared, I could show

to you that a psychiatrist cannot predict well competency. I know of personal cases, people who should have been in the hospital who were able to say what they needed to say, act in a certain way and they got out. I know people who didn't need to be there and were locked up for 100 days, which is \$40,000 of the government's money, and they had no need to be there. In this case, a psychiatrist had confused her physiological disability as being a mental incapacity. So it ranges from the two extremes.

To me, that's why rights advisers in some format are required even if the Advocacy Act is abolished because there is no 100% accurate means of taking away your basic civil liberties because there's basically no trial before we are committed. Some means for those who would want to appeal is necessary. It's to be just fair, and I think it's important if the government doesn't do it, then some well-trained and independent body does it. I have fears that each hospital being allowed to hire rights advisers who will just ensure that whatever the hospital says goes.

I don't know if I should use this or not. As I say, this is the thing for diagnosis. I sometimes think they should include politicians in this, if I might suggest. I know you put in long hours. I know whatever you do, somebody's going to call you wrong and try to abuse you for it. I know for what you do the pay is quite low, so why anybody who is sane and competent wants to become a politician—should become crazy sort of thing. But it's not in the book, so you're okay.

Why I tie into that is, I find it always very upsetting when something goes wrong and somebody kills somebody, injures somebody, like we had recently in Ottawa, and the hint is the person has a psychiatric disability. Immediately on the radio and the TV and in the press, psychiatrists come by and say, "Well, the Mental Health Act is not strong enough that we could lock up this person." I take great exception to that because you get cases—a husband has said very specifically "I will kill my wife," and I never hear the psychiatrist saying "Well, the Mental Health Act is too weak to prevent me from locking up these husbands."

There are some very violent people out there. I know, one of our members in one of the groups I belong to was very violently attacked in the elevator of her apartment, and the guy lives there. He attacked somebody the previous week and he's just a time bomb waiting to go off. I never hear the psychiatrist complaining that the Mental Health Act is not strong enough to lock up these type of people. It's only because we have the stigma of being crazy that the laws change.

I think some of you are aware of what was called the Krueger trial out of Brockville. About two or three years ago one of the people there brought along a friend, a former inmate—this is Lieutenant Governor's warrants—to go for a day pass. As soon as they were out, they killed a third inmate that this person didn't like. For about six months afterwards there were hearings and trials and I kept reading in the papers, "The Mental Health Act is not strong enough to lock up these people." But the fact was, this guy's a Lieutenant Governor's warrant, the doctors had total control of his behaviour but they could not predict that an hour later he would kill somebody.

That's why I want to emphasize that the means for determining our incompetency is quite inaccurate. You have to, in all fairness, provide a means to at least have a second hearing on the matter.

I can ramble for a bit but maybe you could ask some questions.

**The Chair:** We have minutes left, Mr Carne, and we'll start off with Mr Parker.

**Mr Parker:** I think I have about one minute to work with, is that correct?

**The Chair:** One and a half minutes.

**Mr Carne:** With my answer, right?

**Mr Parker:** Mr Carne, maybe all I can do in that minute and a half is just respond to the general point that I take from your remarks this morning, which is that you and others like you suffer a great deal of pain in your condition and we recognize that and I sympathize with that. I do recognize the pain that is associated with the condition you have suffered under and what you have had to endure.

What we have to concern ourselves with is what is the best way to address that pain. If we could wave a magic wand and make it go away, we would do that. There is the presumption behind the existing legislation that the Advocacy Commission has that magic wand, and we question whether it has that effect, or whether it's wiser to let families and people close to the individual affected care for them, take care of them, make the decisions, and assist in that process and not have somebody coming in from the outside and interfering. We just question whether having an outside party interfering is going to assist with the pain at all, or if in fact, it may just add to the pain.

I'm not asking for a comment back from you. I don't know if we have time with the time left. But that's the concern we have with the whole process that we are faced with, with the existing legislation.

**Mr Carne:** I can make two comments. One is, about a year and a half ago when David Reville was first appointed chair, I was at a meeting, and I made the mistake of going off topic and mentioning in passing I think I could tell when people are becoming incompetent, and he tore into me for five minutes. He basically said: "My rights advisers are to give people advice about what their options are. I do not want them to be measuring or determining your competency. If they do, I'll fire them. If they start giving suggestions to these people, I will fire my rights advisers. Their total position is to present people with the options available and let's listen."

And two is, to me, it's better to have somebody who is more neutral, it really is. Family members sometimes get too close and they can't see the wider picture. I know, I belong to the FOS families group and to Depression under Depression, and in both cases the family members—you know, death is a very major option. I think one person out of 10 diagnosed as schizophrenic actually dies, and four out of 10 actually try, so keeping your sons and daughters and family members alive is their prime directive. The other problem is, they are declared incompetent and, a lot of cases, they don't need to be there, and I don't know how you balance that. I don't have a solution to that one.



**Mrs Caplan:** Thank you very much for, I think, a very important presentation to the committee. We appreciate that. The question I have for you is, in the meantime, we know they're going to scrap the advocacy legislation. You've had experience with the PPAO, the Psychiatric Patient Advocate Office. Would you support an expanded mandate for them so that everyone under the Mental Health Act, whether they're in a provincial institution or having service provided from a community mental health program or a community hospital, would at least have access to those rights advisers and advocates under that organization?

**Mr Carne:** I have little association with the provincial psychiatric hospitals, only locally. I used to, five years ago, act as an advocate and people phoned. As I mentioned, there is one case, a woman was in the hospital for 100 days because they couldn't distinguish what her incapacity was—yet definitely some means where an independent person presents people with their options and stops talking and listens, and they say, "I don't want to appeal this," that's it, they leave; they say yes, it goes to the process, just a second court of appeal because you can't predict competency accurately.

**Mrs Boyd:** I want to thank you as well for your presentation. It helps very much and I know it takes a lot out of people to come and talk about their personal circumstances. You might be interested to know that a couple of years ago they tried to put a section in that probably would have covered us all. It was a masochism syndrome, so it may well have had the effect you suggested.

When you talk about the independence of rights advice and the need for people to respect the right of a person once they know what their rights are to have that decision be their decision, do you think that even with this new act it's too complex in many cases for people with the current kind of information that people have to be able to lay out what those decisions are? Would you see a large function being an educational function to enable people to exercise their decision-making appropriately?

**Mr Carne:** I think for most people I know who end up in a hospital, in many cases it's close to the line whether they are or are not incompetent and endanger themselves, and that's the hassle, I really admit that one. But if you're there, even when you don't need to be, it's a sudden shock. You've lost your freedom; you're confined to quarters; you're taking medication which may not be helping you. There are a bunch of other strange people. You're in a hospital setting anyway. To be able to act as your own advocate is a very rare ability under those circumstances.

I've got a fair knowledge of this, at least the previous legislation and I would know enough to appeal for reassessment, very likely do it competently and go through the hassle. I know just trying to get a form for somebody else from the hospital is a real big hassle. They say, "We don't have them." You say, "You have to have them." Then they talk, "Oh yes, we do," and they go to some back file. It's a real hassle to act as your own advocate when you're in the hospital.

**The Chair:** Thank you very much, Mr Carne. I know how stressful it is, not just yourself, but for all of us, and we appreciate your presentation today.

**Mr Carne:** Thank you.

**The Chair:** We will be recessing to 1:20.

*The committee recessed from 1204 to 1320.*

#### ROBERT FROOM

**The Chair:** Our first presenter, in substitute for the person who was listed, is Mr Robert Froom. Mr Froom, could you tell us on whose behalf you are speaking?

**Mr Robert Froom:** I'm speaking as a private citizen. My brother is a vulnerable person.

**The Chair:** Fine. The floor is yours. You have 20 minutes, including questions.

**Mr Froom:** As I say, I'm coming here as a private citizen. I'm not associated with any particular agency, but I felt it was very important for me to speak to the subject of the Advocacy Act and to speak against Bill 19.

I'm here to bring to your attention the consequences of not having a systematic method of ensuring that vulnerable people's rights are respected. I bring with me 40 years of personal experience on the matter and over 100 years of family history. I know the limitations and capabilities of families, and I have no interest in returning to the days when families took care of their own.

Just to give you some background, my brother suffers from a condition called Norres disease. It's only recently been understood. It resulted in him being blind at birth and developmentally delayed, and in his middle age he has gone completely deaf. He is a vulnerable person, and I'll go into more detail. It's a genetic disease and I've had three uncles who suffered from the same condition. A hundred years ago, there were two other members of our family who suffered from this disease. I can draw on a lot of experience. I'm bringing it to you today because I think it has relevance to the Advocacy Act and Bill 19.

It would seem that the intent behind Bill 19 is to reduce government interference into private lives. It seems to be based on the assumption that the Advocacy Act is too intrusive. "Leave well enough alone" seem to be the operative words, yet there are vulnerable people all over this province who need a voice and who deserve to live better lives. They used to live in attics and basements. A hundred years ago, they were seen to be God's punishment and quite literally they never saw the light of day.

Today, we would want to rescue a person who was confined in such a way. We would want to protect a person from abuse by his family. But this bill seems to think that intervention into family matters would be just too intrusive.

We all agree that the state has the right to interfere where our fundamental rights are abused or that the state has the right to expropriate land for roads. Why, then, would the government not act on its responsibility to protect all its people and to support advocacy for the rights of vulnerable adults?

There seems to be an idea that families are best suited to advocate for their disabled family members, but there are problems with families taking on this responsibility. Vulnerable people cannot pick their parents. Not all families have financial resources. Not all families are stable. Many vulnerable people do not have families at all, or worse, they've been abandoned by their families.



Two generations ago, my grandfather was a farmer in southern Ontario. Actually, just before that he was a school principal in northern Ontario. He held a very responsible position. But in 1925, he moved his family south to take up farming because it was becoming increasingly difficult to serve as a school principal with three of his five children blind and developmentally delayed. Socially, at that time, it was a stigma to have disabled children.

The Depression was hard for farmers and it was hard for him, and after 10 years of trying to cope, he lost his farm for unpaid taxes. By this time, one of the boys had died of accidental causes in the home. So he put his other two blind and developmentally delayed boys into his car and he drove them to Toronto, where he left them in an institution. He went back to northern Ontario to work in the mining industry in menial labour, and when he got his feet under him he sent for his wife and his normal children. He never saw his developmentally delayed children again.

Most families are caring and loving, but cannot face the responsibility of caring for a family member indefinitely. A generation ago, one of the children who was left in that institution in the 1930s—he's my uncle—had made his way to live with my parents and their young family. He lived in the attic and spent his days stripping insulation from copper wires as occupational therapy. When my brother was born blind and developmentally delayed, the family just could not handle the strain. My uncle drifted down to Toronto, and without proper supports, he slipped deeper and deeper into institutionalized life. By the 1960s, he was diagnosed as being deeply depressed because he no longer spoke.

What was not understood at that time was that he was losing his hearing and that he was increasingly being cut off from the world around him because he was already blind. Eventually, he was given extreme forms of therapy for his wrongly diagnosed depression. It's a tragedy.

I am convinced that advocacy would have significantly changed the direction of my uncle's life. His hearing loss would have been identified and he would have received intervention services earlier in his life. He died last November, after a long and lonely struggle.

Presently, my brother is 52 and he is both deaf and blind. He's developmentally delayed and he lives in a nursing home. He has been living in homes for the aged since they were called that, about 28 years, to be precise. Being both blind and almost totally deaf, he is increasingly cut off from the world around him. In general, people are unable or reluctant to communicate with him. Often, he goes for days without meaningful communication. He has caring and loving parents and brothers and a sister who love him dearly, but this is not enough.

Thirty-four years ago, when my brother David was 18 years old, he was no longer qualified for public education and his parents were faced with difficult decisions about his future. They consulted the family doctor, who brought in a psychiatrist, and on the basis of very little information and faulty judgement, they had my brother admitted to Brockville Psychiatric Hospital. What really needed to be addressed at that time in his life was a need for housing.

### 1330

He was there for four years and complained that he was not allowed to wear his own clothes and that other patients harassed him about sexual matters. Now, over a quarter of a century later, my brother still says frequently when I visit him that he forgives his family for making such a terrible mistake.

My brother was eventually discharged from the hospital and was found, two weeks later, in a state of extreme anxiety in a nursing home 100 miles away. It seems that the hospital had neglected to tell my parents that he was being discharged, nor did they tell my brother where he was going. I am certain that if the Advocacy Act was in effect in the 1960s, my brother's life would have been less emotionally scarred.

Today, my brother receives 10 hours of intervention from CNIB deaf-blind services each week. His CNIB intervenor is his lifeline to the world around him and she helps him communicate with fellow residents, the nursing home staff and his family.

Until last fall he received three visits from his intervenor each week. I'd like you to imagine what it would be like to receive three visits a week and during those visits you must do all your communication, during those 10 hours a week. We know there is no other communication when his intervenor is not there.

Due to provincial budget cuts, his intervention time has been consolidated into two visits per week to save on transportation costs. This is an intolerable reduction in his services. At a time when my brother is facing the total loss of his hearing, the very services that help him connect to his world are being reduced. David needs an advocate who understands the system to ensure that he gets the services he needs and to lobby for the services that he needs but that so far do not even exist.

Communication is my brother's biggest need. He needs more intervention time, not less. The consequences of not receiving intervention services are well known from our past experience in the family.

I attended a meeting last night for the family members of vulnerable people receiving case management from an MCSS-funded agency. We were told at that meeting that the agency providing case management to my brother had lost its contract to do so and that a new agency would be taking over his file. This is not in itself a tragedy; things like this happen. But it is a tragedy that my brother's file has been bounced from agency to agency over the period of years. In the past four years, his file has been handled by three different agencies. This is after a period of about five years of being on a waiting list.

These are the people who are supposed to be advocating for services for my brother and addressing his urgent need for community-based housing. Due to his communication deficits, none of the case managers has gotten past the friendly visit stage, the very earliest stage in the intake process. No progress has been made—none.

The tragedy of other generations is repeating itself and my brother remains in a nursing home—not in an attic, but he is out of sight. This is the part that concerns me most: My brother is not unique; in fact, he's typical of vulnerable people. In recent weeks, the sheltered workshop at Silver Springs Farm has been closed, sending



numerous developmentally delayed workers back to the limited resources of their home.

Tonight there's a meeting at Algonquin College to discuss the termination of a program for developmentally delayed individuals. As one developmentally delayed client of community integration service put it at last night's meeting, "We are never informed about these changes; they are always done to us." We should all be listening carefully to the vulnerable people across this province who are having services withdrawn and their rights removed by Bill 19. At this critical time, a time when new directions are being set and difficult decisions are being made, we need the Advocacy Commission and the Advocacy Act more than ever, yet this is the very time the Advocacy Act is being repealed by Bill 19. Shame, shame, shame.

That concludes my presentation.

**The Chair:** Thank you, Mr Froom. We've only got two minutes left, so you're going to be limited to about 30 seconds each. Mr Duncan?

**Mr Duncan:** No questions. Thank you for a very profound presentation.

**The Chair:** Third party?

**Mrs Boyd:** I think you and your family were promised that disabled people would not suffer as a result of the changes, and you've told us that you are. Thank you.

**Mr Klees:** Thank you very much for your presentation. It's occasions like this that certainly help us and guide us. I can just assure you that the government will do everything it can to ensure that advocacy in this province will continue on an effective basis for people like your brother. I also want to say thank you for the advocacy that you represent, because you've certainly advocated very effectively today.

**The Chair:** Thank you for your eloquence, Mr Froom. Unfortunately, that's all the time—

**Mr Marchese:** There must be time. I think he wanted to reply to Mr Klees's comments.

**Mr Froom:** Just because I'm here does not mean that families can adequately advocate for their loved ones.

**Mrs Boyd:** Mr Chair, I wonder if I could table a document with the committee. I have in hand the jury recommendations stemming from the evidence in the Lonnie Clemens inquest. I would like to table these and ask for them to be circulated to all members.

**The Chair:** We agreed that would be tabled. Thank you very much for obtaining that, Mrs Boyd. The clerk will have them copied and distributed to the members.

#### CANADIAN COUNCIL OF THE BLIND KINGSTON FRIENDSHIP CLUB

**The Chair:** Canadian Council of the Blind Kingston Friendship Club, Mr David Renwick.

**Mr David Renwick:** First of all I want to thank you for allowing me to address the committee, and I'd like to briefly introduce myself. I am a visually impaired male. The medical term for my visual impairment is congenital aniridia; that is, in layman's terms, I have no iris in my eyes, which is the blue part or brown part. While I do not consider myself mentally incapable or developmentally challenged, this condition is oftentimes associated with mental retardation.

I am here, however, as a representative of the Canadian Council of the Blind, which is a national, non-profit, charitable, self-supporting and consumer-driven organization. We are a friend, advocate and educator of blind and visually impaired people across Canada, their families and friends.

There are some 1,800 blind, deaf-blind and visually impaired people in our area. Add to this the number of people simply enrolled with the Canadian National Institute for the Blind and visually impaired as a result of other medical problems, and you can see that there's quite a wide base.

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I am here today because the membership of the Canadian Council of the Blind Kingston Friendship Club has some great concerns about repealing the Advocacy Act. We feel there is a need for advocacy. There are many things to be advocated, especially on a systemic level. Employment is one of these things, and if I can, I'd like to briefly use myself as an example.

There is, I suppose, some small minority of people who appear content to exist quietly on social services, but there are a vast number of people who want more than just a job. We want a career, and as I said, I'd like to use myself as an example. With the help of vocational rehabilitation services and the assistive devices program, I have gone to school and I've studied hard. Now the Ontario government says I'm qualified as both a hairdresser and a developmental services worker, but it is still impossible to find a job due in large part, I feel, because of my vision.

Some other issues that need to be advocated are access and safety issues. It does no good to build wheelchair ramps on sidewalk curbs if people in wheelchairs can't get into stores; or if a store or a public building is wheelchair-accessible, it is oftentimes accessible through some dark alley and you have to wheel past a garbage bin and through a back door somewhere. That's just not right. We are people too and should be able to use the front door.

Public transit is another example. Kingston Transit, as opposed to OC Transpo, has black handrails on a black door and that is very difficult for people who are visually impaired or totally blind. The other thing that Kingston Transit has is white edging on the bus steps. This was put there as a result of Ontario seniors lobbying to have that put there. What I would advocate is that that white edging simply be changed to yellow so that it can serve two groups for the same cost. I don't imagine the cost between white and yellow paint would be terribly different.

There are many other issues to be advocated as well. There are health care concerns, and I will direct your attention to the last four pages of my brief, which talk about laser eye surgery and how it can correct myopia. Yet the Ontario government and OHIP say it's cosmetic surgery. It seems to me there's a certain logic in there, that if one can correct a person's handicap and get them off social assistance and into the workforce, the government would actually save itself some money. Other issues to be advocated are such things as safety concerns, audible signal lights, that sort of thing.

While it can be argued that the Ontario Human Rights Commission could possibly advocate some of these issues, it is clearly not prepared to handle all of them. Based on its policy of putting conditions on having, say, a driver's licence as a condition of employment, in one breath the Ontario Human Rights Commission says it is discrimination to say that you need a driver's licence and in the other breath it says it's not discrimination because people are accustomed to cars and depend on them. Unfortunately, blind or visually impaired people don't have that luxury. Unfortunately, the Ontario Human Rights Commission just is clearly not prepared to handle these things for us.

If the idea behind Bill 19 is to be financially responsible, that objective is fine, but the problem is in how we reach that objective. The Ontario Ministry of Community and Social Services no longer has its Council of Consumers which was set up four years ago to be a voice for its clients. Also, Community and Social Services no longer is guided by the Challenges and Opportunities multi-year plan. It seems to me that if the idea of saving money is the objective of Bill 19, full integration into the community is just as true today as it was four years ago. The need for advocacy is just as great today as it was four years ago, for advocacy means giving people the opportunity to make informed choices. Living in the community does that; it gives us that opportunity.

I would just quickly close with saying that I would be remiss in my responsibilities as an advocate if I did not suggest that there were some other things that the Ontario government could look at in saving money; things like dispensing fees for prescription drugs—there's quite a vast difference. The Ontario government helps pay for these things through family benefits or other social assistance programs and also helps to pay for these things for senior citizens. I'm sure that if it were to look at the dispensing fees, the Ontario government would save itself some money.

There are some other ideas which unfortunately time and financial constraints just don't allow me to bring here, but I would be happy to answer any of your questions if I could.

**Mrs Boyd:** Thank you very much for your presentation, Mr Renwick. I really appreciated it.

You spent a lot of time in your presentation talking about the desire of people to be self-sufficient and to be able to live independently, and about the problems around employment. Of course, one of the real issues for us is that in addition to the disappearance of the Advocacy Commission, this government has also repealed the Employment Equity Act, which was designed specifically to assist people who face the kind of employment issues that you deal with. So you're really bringing to our attention the fact that there's a cumulative effect of things that have happened to you and to the people on whose behalf you advocate under this government. With employment equity disappearing, now the Advocacy Act disappearing, the changes in social assistance, the changes in terms of the drug benefit plan, it all adds up to a very bleak picture, does it not?

**Mr Renwick:** It does, yes, not to mention the more recent changes in Bill 26 as well.

**Mrs Boyd:** Yes. So the need for advocacy that you talk about is probably going to be greater and greater as time goes on, as people find themselves in more and more difficulty trying to maintain their self-sufficiency and their dignity in the face of these changes.

**Mr Renwick:** Right.

**Mr Marchese:** Just as a brief question, you heard the previous speaker, Robert Froom; I think you were here to listen to the previous speaker, were you not?

**Mr Renwick:** Yes, I was.

**Mr Marchese:** He makes a strong plea for retention of advocacy advisers, for advocacy in general. He points out that sometimes families are not there to help individuals who are not capable, or sometimes don't have the wherewithal or the means, or it's difficult, and that it's important to have advisers and an advocacy commission to help people who need those services. Do you have a comment in that regard?

**Mr Renwick:** Yes, I do. Mr Froom's presentation was quite good. The obvious thing here is that as the need for advocacy becomes greater and greater, I believe what you're going to find, and it has started already, is that groups are going to spread out. If I can again use the Canadian Council of the Blind as an example, I'm here representing them, but we have people who are diabetic, people who suffer from multiple sclerosis, people who have cerebral palsy, to name but a few. That is going to happen more and more, that there are cross—and that's great, because the more we work together, the better we can make things happen.

1350

**Mr Clement:** Thank you again, Mr Renwick, for your presentation. I just wanted to springboard off something Mr Marchese said. Maybe you'd like to respond to this. Effective advocacy existed long before the Advocacy Act, existed during the Advocacy Act, and it's going to exist after the Advocacy Act. The Advocacy Act doesn't eliminate advocacy. What it does, in our view, is deinstitutionalize it again, put it back into the friends and family in most cases, where that is appropriate, and allows them to be close to the people they love. I think we're all in favour of advocacy; it's a question of how you construct it in one's society. Does that make sense to you at all?

**Mr Renwick:** Yes, it does.

**Mr Clement:** Much of what you said had to do with something we haven't talked a lot about directly: systemic advocacy, advocacy for change of the way various persons in our society are treated or have to struggle. I'd like to get a handle from you about some of the advocates for change already in the system even without an Advocacy Act. I'm thinking of the Ontario Advocacy Coalition and ARCH, two very articulate institutions and spokespersons for disabled persons. Are they not doing a good job, or how do you feel about them?

**Mr Renwick:** I can't say with any great degree of honesty that they are doing a good job or a bad job. I know they exist, from a personal standpoint, and that's really about all I can say. I know from experience in working with handicapped people that a lot of the people I talk with don't know they exist, so I would have to say they may be doing a good job but they could do better, especially at getting their name out there.



**Mr Clement:** We've got to work together to strengthen the volunteer sector on advocacy so they can do a wonderful job independent of government. I think advocates are strongest for their cause when they are independent of government. That way, they have much more credibility and legitimacy. But I thank you for your comments.

**Mr Duncan:** You spoke quite well about your views about the repeal of the Advocacy Act, and the government has brought forth the Health Care Consent Act. Given that the government will repeal the Advocacy Act, do you have any comments specific to the proposals contained in the Health Care Consent Act and the Substitute Decisions Act amendments that might help us in formulating amendments that will provide at least some enhanced advocacy.

**Mr Renwick:** It's my personal feeling that there are some concerns. Alarms bells went off in my head when I was reading the proposed changes to the Consent to Treatment Act which specifically said that, given consent, the doctor is then allowed to presume you give consent to alternative treatments. Knowing that there are people out there who have allergies and such, and possibly a limited capacity to appreciate a whole lot of information and still make an informed choice, that gives me a little bit of cause of concern. Substitute decisions? I really am not a whole lot comfortable with that yet. I only recently, within the last two weeks, got my hands on Bill 19, and it's been an awful lot of reading just to do what I have done with regard to the Advocacy Act.

**The Chair:** Thank you very much, Mr Renwick, for your well-written brief. The committee thanks you.

#### COUNCIL ON AGING—OTTAWA-CARLETON

**The Chair:** Our next submission is from the Council on Aging of Ottawa-Carleton; Marian Chapman, president. Ms Chapman, perhaps you could identify those appearing with you.

**Ms Marian Chapman:** I will. With me are Nicole Guénette, Carol Burrows and Jim Lumsden.

Mr Chairman and members of the committee, the Council on Aging—Ottawa-Carleton, is a non-profit planning, coordinating and advocacy organization serving 70,000 residents of the region of Ottawa-Carleton 65 years of age and over. One of the fundamental roles of the council is to study issues and advocate on behalf of the senior consumer when appropriate.

In responding to Bill 19, we have collaborated with other groups whose focus is support of vulnerable persons in order to bring a holistic approach to the issues. The names of all members of the task force are listed on page 9 of our brief.

With me today are Carol Burrows, from Disabled Persons Community Resources; Nicole Guénette, from Psychogeriatric Community Services; and Jim Lumsden, who is a family representative.

The scope of our brief: The government has previously given heed to the many expressions of concern during previous public consultations on the Advocacy Act, 1992, and its companion legislation, and the experience gained since its proclamation last April. We commend them for this. However, there remain some concerns, which we

would like to comment upon today. We will make recommendations which we put forward for your consideration during your clause-by-clause study and the subsequent development of regulations under the acts. In the interests of time, I will be summarizing the information contained in our brief.

Our first concern relates to protection for vulnerable persons. The purposes of the Advocacy Act included contributing to the empowerment of vulnerable persons through the promotion of respect for rights, freedom, autonomy and dignity and providing advocacy services. Its repeal removes any formal mechanism for a legislated or authorized advocacy system for persons, wherever they reside. There is a need to coordinate the efforts of families and other volunteers who provide services and assistance to vulnerable persons.

The aim would be to supplement these efforts with advice, assistance and support, so it is recommended that a replacement group be established which will undertake a review of means to provide support, assistance and coordination of those many family members and existing volunteer organizations who undertake advocacy tasks for vulnerable persons regardless of where they may be in the community.

#### 1400

Now to advocacy. Our recommendations for the provision of advocacy are addressed according to the settings where vulnerable persons are encountered: residents living in facilities, persons receiving care in the community and, finally, individuals residing anywhere within the community who are neglected, abandoned or abused.

Regarding advocacy in long-term-care facilities, a capability to undertake advocacy is required for both residents who have substitute decision-makers and those residents without family or friends to speak on their behalf. In addition to dealing with advocacy issues within the facility, there is a need to maintain contact with external agencies whose policies and sphere of influence affect the quality of life and care of residents. This might be accomplished through family or volunteer participation on residents' councils. However, residents' councils as they currently exist are not the appropriate vehicle, due to the ever-advancing age of entry and increased care needs of residents.

It is therefore imperative that a means for such advocacy be established. This could be instituted through several possible mechanisms; one is the revision of the role and function of residents' councils, with the inclusion of strong substitute decision-maker representation; another is the inclusion within the legislation of a mandatory requirement for an advisory board of substitute decision-makers and family members.

Although beyond the scope of the present discussion, we also urge the government to develop a mechanism for advocacy whereby residents of retirement homes and other care facilities which do not fall under the jurisdiction of the present legislation will be adequately protected.

Therefore, our recommendation is that Bill 19 make provision for the establishment and empowerment of a body within long-term-care facilities which is mandated to provide advocacy on behalf of the residents.



Next we deal with advocacy in the community. The wide dispersion of care delivery in the community requires another type of mechanism to link vulnerable persons with those who could advocate on their behalf. It is suggested that this could be done initially by the provision of details of such assistance at the time of seeking service through the new community care access centres. This process could clearly set out a person's entitlements, rights and reasonable expectations and advise them on how to make contact with the volunteer advocacy groups for the help they may need.

Therefore, we recommend that community care access centres be required to develop a capacity to advise on the availability and means of contact with existing community advocacy services.

Finally, advocacy for individuals who are neglected, abandoned or abused. There are many persons who are not in receipt of care in either a long-term-care facility or through community services. Individuals who are neglected, abandoned or abused are the most vulnerable in our society and lack family or friends to speak on their behalf. There is a need for a proactive advocacy capability for these persons who may not be capable of, or are prevented from, seeking advocacy assistance. It is critical for the safety of such persons that there be a mechanism for rapid intervention to assert their rights. This capacity must be legislated and supported with the necessary authority to inquire into cases of potential abuse, neglect or abandonment. This would include provision of right of entry under closely controlled circumstances.

A close relationship with the office of the public guardian and trustee would be essential in these situations. It is noted that the Substitute Decisions Act, subsection 87(1), now provides for that official to appoint volunteers to provide advice and assistance. There is a lack of clarity regarding the intent of this section, including the role, recruitment, selection and training of these volunteers. It is unclear whether the volunteers would be able to meet the advocacy needs of this group of vulnerable persons.

Our recommendation is that there be a capability to coordinate the efforts of the volunteer advocacy and support services agencies which act as advocates for persons who are neglected, abandoned or abused. Persons who serve in such a capacity must be provided with adequate authority and rights to perform in an effective manner. This would include the right of entry. We also recommend that the role of volunteers referred to in subsection 87(1) of the Substitute Decisions Act be clarified in the legislation.

Our next comments concern the scope of practice for health practitioners. The legislation states that health practitioners can override the decision of the substitute decision-maker in cases regarding emergency treatment and treat, despite refusal, if they feel that the substitute decision-maker is not operating in the best interests of the individual. As a safeguard, it is recommended that in circumstances where a health practitioner proposes to override the decision of the substitute decision-maker, a second opinion be obtained where the situation makes such a second opinion reasonable under the circumstances.

It is also important that advance directives or living wills be given recognition in the legislation, since at times the decision not to treat, even in the case of an emergency, has been a well-thought-out decision.

Therefore, it is recommended that the primacy of living wills and/or advance directives as the considered and expressed wishes of the incapable person be given formal recognition in the legislation.

We now address capacity assessment. An issue which has come to our attention relates to the difficulty in accessing capacity assessment services in the community. Capacity assessment can now be done in only two ways: The first is through admission to a schedule 1 facility for a determination of capacity, at no cost to the individual requesting the assessment; the second is by certified assessors in the community, at considerable cost to the person requesting the assessment.

The method of determining capacity through admission to a hospital is counterproductive, given the cost to the system and the fact that hospital bed closures are imminent. This will undoubtedly increase the pressure on the remaining institutional beds. It is obvious that people who require a capacity assessment and, in certain instances, are living in the community at considerable risk to themselves and their neighbours will not be well served by the inevitable delay this will cause.

In addition, the high cost entailed in obtaining an assessment in the community by certified assessors results in assessments simply not being done in many cases because, with the present rules, outside a hospital setting the person who requests the assessment, not the patient, is responsible for the prohibitive cost involved.

We are therefore recommending that psychiatrists affiliated with community psychiatric services which are associated with a schedule 1 facility be able to perform capacity assessments in the community.

We now move to the Consent and Capacity Review Board. Bill 19 authorizes panels of single members to deal with particular applications. The impact of decisions on the life, dignity and wellbeing of the individual suggests that more than one person should be involved in a hearing in order to avoid possible prejudice or bias. The former requirement for written reasons for decisions on a universal basis has been amended to require such reasons only when they are requested.

We have two recommendations on these issues. It is recommended that a panel consisting of three members be the minimum required for a hearing. It is recommended that the present proposal whereby reasons for decisions will only be provided on request be amended to require that the board provide each party or the party's counsel or agent with written reasons for its decision within two business days after the end of the hearing. It should also provide that such reasons shall be accompanied by a notice of right of appeal under subsection 78(1) of the Health Care Consent Act.

We come now to communication. Subsection 23(3) in the Health Care Consent Act states that the initiation of emergency treatment may be undertaken without consent from a capable person due to a language barrier or because the person has a disability that prevents the communication from taking place. It is essential that such



inability to communicate not be mistakenly attributed to inebriation or mental incompetence. It is crucial that health practitioners be aware of alternative forms of communication and that the capability to access such alternative communication form a part of the operational procedures where emergency treatment is generally delivered.

Therefore, the recommendation is that regulations developed under the Health Care Consent Act clarify what would constitute reasonable steps envisaged under clause 23(3)(b) when providing such emergency treatment to capable persons without their consent.

In closing, we commend the government for its action in clarifying and simplifying existing legislation related to advocacy, consent and substitute decision-making. There are, however, some remaining concerns, which we have set out in our submission. These are elements critical to the protection of vulnerable citizens and we forward them for your consideration of amendments to this proposed legislation. Thank you.

1410

**Mrs Johns:** Thank you for your presentation. I just want to explore a couple of things with you, if I might. In your recommendation 7, talking about advance directives, advance directives or wishes expressed by a person do take precedence over any other circumstance. I am unsure if you're coming at something else by this comment, but an advance directive basically is precedent unless there is some reason to believe they haven't expressed a wish after that time frame. It's important to realize that advance directives will be given the priority they deserve, so you can set an advance directive and it will be recognized.

**Ms Chapman:** We didn't see the actual words "living will" and "advance directive" in the document.

**Mrs Johns:** I can find you the subsections and let you know. Section 4 is where we're talking about that. So it's just that you want to see the words in there?

**Ms Chapman:** Yes.

**Mrs Johns:** Okay, thank you. In section 9—I've been on this all day. I don't know if you've been around all day and have heard this.

**Ms Chapman:** I haven't been here, but I listened in Toronto.

**Mrs Johns:** Coming from rural and northern Ontario, it sometimes takes up to seven days to get a board of three people together to ascertain that we can move forward. That's way too long, and in some particular circumstances we have to look at a one-person board just to be able to move forward. We've made some pretty stringent requirements, I believe, about who this person can be, ie, they have to be a lawyer; they have to have been on a board prior to this time; they have had to be on the board for two years; they have to have had experience with the particular topic they're adjudicating in this circumstance. I believe we have safeguarded the person but that this allows us to move on in the case where we need to have this go quickly. Do you have a problem with the one-person board under those circumstances?

**Ms Chapman:** Yes, we do, and the task force dealt with that at great length. We certainly felt that one person could lead to a certain degree of bias or prejudice and that three persons was a better solution to this issue. Nicole, would you like to comment on that?

**Ms Nicole Guénette:** All of us have some racial or significant prejudice sometimes—it's probably not voluntary but it's sometimes there—and we've felt that more than one person would eliminate the possibility of any kind of prejudice in any decision, especially when you're looking at capacity and these issues that are very delicate because we're dealing with stressed families or neglected individuals. I can see your point of view as to rural areas, that it can become difficult, but I think prejudice and bias are always present. It's just to eliminate that aspect. It can be the best person in the world, the best lawyer with the best experience, yet there are circumstances where more than one protects that eventuality from happening.

**Mr Duncan:** Your recommendation 2, that Bill 19 make provision for the establishment and empowerment of a body in a long-term-care facility—I presume you're saying a body that would be independent of the facility itself and would have its own governance structure.

**Mr Jim Lumsden:** Yes. We would see it as being entirely independent from the management of the home.

**Mr Duncan:** And that's because of potential conflicts of interest?

**Mr Lumsden:** Yes, and of course that leads to the extension of having some coordination capability that the board can talk to, external to the home.

**Mr Duncan:** Further to the point raised by my colleague opposite about the single-person hearing, the concern we share with you is that I know lots of lawyers who've been out 10 years that I would not want arbitrating on my behalf, quite frankly. I think you answered her question very properly. We'll be bringing forward some amendments around that whole area.

**Mr Ramsay:** You talked about establishing a replacement group to conduct a review. Do you see that group potentially having additional powers after it would do that, maybe giving it the power to allocate resources to fill up some deficiencies in the province, if they were to find some?

**Ms Chapman:** We were not providing a solution here. We were just indicating areas that we felt needed to be addressed, so we did not deal with solutions.

**Mr Lumsden:** What we would like to see, though, is the capability to provide programs of public information. As Mr Renwick said, in response to Mr Clement's question about ARCH and the Ontario Advocacy Commission, there is a requirement for public information. Someone must be coordinating that type of information going to the public. There is a need for someone who has a full understanding of advocacy as well.

You dealt with Mr Froom's issue of out of sight. Mr Froom's brother is lucky he has a brother who is that active. What will we do with a person who is very deep out of sight? This group would look to this sort of thing. Eventually, you may see us referring to the power of entry we would like to see be established.

**Ms Carol Burrows:** When we're talking about people having families, the families do not always act on behalf of the person, even when they are present. One regrets having to say that, but all of us who work in the community know it's true.

**Mr Marchese:** I want to make some comments by way of agreement with a number of the things you've

said. One of them has to do with the point you made around communications on page 7, saying that, "It is crucial that health practitioners be aware of alternative forms of communication." I believe that's fundamental.

A woman appeared in front of our committee who was deaf and could not speak. What reasonable steps do we take to understand that particular kind of difficulty? I like what you said in there—well, it's hard to find the points in the brief, but we'll go back to it. I just think that your observation is an important one.

With respect to the Consent and Capacity Board, having more than one panelist has been a recurring theme with people here. Government members try to justify it in their own way in terms of why one and that in northern regions it would be difficult to get two or three, and so on, but the majority of people who've come in front of this committee from a number of places have said, "You need more than one person."

There's something that informs you about why we need to have more than one person, that when you're dealing with capacity it isn't a matter that one individual has the ability to reason and all that. When we're dealing with capacity, a number of things come into play, and to leave that in the hands of one individual is a problem. You identified bias or prejudice or discrimination as something we should also look to, that having a second person there is sometimes a security or a check in that process.

I wanted to get to some of the areas you talked about in terms of advocacy, because a lot of what you said here is really what we were trying to implement through the Advocacy Commission. Although you're recommending different things about how to create advocacy, essentially the Advocacy Commission was trying to do this.

What Mr Froom identified earlier, and so many others, is that we need advocacy. Volunteers are fine, but they don't have the expertise. Families are good, but they don't have the expertise at times; they burn out. Some of them are not capable. Some of them are abusive. What all of you are pointing out is that the state, contrary to what Mr Clement says, needs to be there to provide the rights advice, that we can't simply hope that the volunteers and the families are always going to be there doing the advocacy for those poor vulnerable people; that we as a government have a responsibility to put something in place to make sure that vulnerable people have something to hang on to. Any comment on that?

**The Chair:** Thank you, Mr Marchese. We have to proceed.

I thank you very much for the care and the trouble that's gone into your presentation. I noted you had 14 on your task force, and I can imagine the time it took to reach a consensus.

**Mr Ramsay:** I think the record should show they nodded.

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#### ONTARIO RESIDENTIAL CARE ASSOCIATION

**The Chair:** Our next submission will be from Mr David Porter of Bearbrook Court Retirement Residence. Welcome, Mr Porter. You're not associated with Bearskin Airlines or anything like that?

**Mr David Porter:** No.

**The Chair:** I was declaring a bias. If you would proceed, sir.

**Mr Porter:** Thank you, Mr Chairman and members of the committee. The Ontario Residential Care Association, or, as we call it, ORCA, is a voluntary organization of owners and operators of retirement and residential care facilities. ORCA was founded in 1977 and currently represents more than 220 care homes providing assistance with activities of daily living for about 15,000 residents. ORCA member facilities employ more than 10,000 staff.

Across Ontario there are approximately 23,000 residential care beds. The average age of residents who occupy those beds is about 84 years old, an increase of five years from a decade ago. In some jurisdictions across Ontario, residential care facilities are also home to a younger population of disabled or post-psychiatric patients.

Residential care plays an important role in the long-term-care continuum. We fill the increasing gap between home care services and the extended care support delivered by nursing homes and homes for the aged. As our population continues to age and the demand for a limited number of long-term-care beds increases, we fully anticipate the contribution of retirement and residential care services to continue growing.

We participated in the committee hearings involving the Advocacy Act, the Substitute Decisions Act and the Consent to Treatment Act in the early stages of the previous government's mandate. Like many health care provider groups across the province, we expressed concerns about the Advocacy Act.

We argued that by its own definition in section 1 of the act, a successful advocacy initiative should result in the need for few, if any, provincially designated advocates since the spirit of the concept involved moving towards self-advocacy. In fact, the residential care environment has long promoted the rights of residents to make personal decisions. It is our strong belief that delivering quality care can only occur when done in a setting that encourages individual dignity and autonomy.

Our association urged the previous government, at a minimum, to test its Advocacy Act on a pilot basis. We were concerned with the complexities inherent in a system which involved reporting to a commission through untold numbers of quasi-judicial advocates handed extremely broad mandates.

Most importantly, we were concerned with a system that appeared to promote confrontation between caregivers and advocates. The act gave advocates the right to enter any building on the reasonable belief that there were vulnerable people inside. In fact, this meant that an advocate could enter a residential care facility at any time and go on a fishing expedition for advocacy issues. Then, with almost as little basis for their action, they could tie up valuable staff time searching for and copying records. Warrants were either not required or could be obtained without naming a single vulnerable person.

We have registered staff in most residential care settings. We also have qualified support staff who contribute to a supportive and compassionate environment, and we strongly believe our staff is committed to delivering care that is in the best interests of our residents.



We applaud the government's move to repeal the Advocacy Act and, given the nature of our client base, we further endorse changes involving substitute decision-making and consent to treatment intended to reduce red tape and strengthen resident support. Examples can be provided in the question period, if you wish. The rest of the presentation will concentrate on issues of particular concern to us; that's examples of particular things that we support in the legislation.

Our experience in the residential care sector is that families or designates often play a participatory and caring role in meeting the changing needs of our residents. Although our services are predominantly private-pay, we have historically experienced limited problems with payments. In the odd case where a family member or designate appears negligent, we agree with the concept of contacting the public guardian and trustee as a last resort.

We believe that rights advice, as it is currently detailed in the act, is a system that is restrictive and one-dimensional. We support the government's position to delete the rights advice from the Consent to Treatment Act.

People familiar with residential care settings will know that, as a standard of practice, registered staff will provide rights advice. Non-registered staff, such as administrators, who are generally sensitive and informed are also capable and willing to provide residents with rights advice. We prefer the flexibility inherent in removing the cumbersome system as it currently exists.

We suggest that there may be merit in applying the hierarchy of consent in section 18 to include residents of residential care and retirement homes, rather than just stopping at the nursing home level. It seems impractical and costly to force family members to hire a lawyer to arrange for power of attorney in cases where residents are deemed incapable of making a decision. If you want further explanation of that point, I can do so.

We wonder if there may be further merit in expanding the personal assistance plans to include services beyond long-term-care facilities. As you know, personal care planning is equally important in the delivery of chronic and residential services as it is in nursing homes and homes for the aged.

We are concerned, however, that the capacity threshold as proposed in Bill 19 may be too high. We believe that the proposed concept may be counter-productive if approval for a care plan by a substitute decision-maker overrides the ability of residents to make routine, daily decisions involving their personal care. Encouraging residents to participate in routine decision-making is a vital component of any meaningful personal care plan. Again, I can provide an example of that.

There is another area of concern which we believe should be considered prior to the passage of Bill 19. About 18% of our residential care population rely upon general welfare assistance. This program was initially set up for frail elderly people who require funding support. However, over the years GWA recipients have become predominantly post-psychiatric patients.

In GWA cases, agreements to meet an individual's care needs are handled directly between a local social services agency and an approved residential care operator. A condition of residency for any post-psychiatric patient

who chooses an approved residential care facility involves care plan compliance. These care plans are developed in co-operation with a person's physician, social services and the residential care facility staff.

If there is an Achilles' heel in the system, it involves the post-psychiatric patients who, after living in a stable residential care environment for a period of time, opt to lead a more independent life in the community. This is their choice; in fact, this is the goal that the province and the caregivers hope to achieve for these individuals.

It is, unfortunately, not always a realistic goal. It's our experience that many of these individuals return to the system soon after they exercise their choice. The absence of a stable living environment, which fails to provide the necessary nutrition and medication regimen, contributes to the revolving door syndrome that our residential care operators often witness.

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Typically, GWA residents lack family support. Because they are usually considered competent, there is no involvement with the public guardian and trustee. We know that, through a structured environment, many GWA recipients are capable of participating in community programs and even holding jobs. We believe the revolving door problem is very real, very costly to the province and counterproductive to the individual. Perhaps a more thorough assessment by area social services is required when a person requests a move from a residential care setting into the community. A review of one's condition, history and previous experiences in the community might be a prerequisite to approving any move into the community. We know this recommendation does not fit nicely into either the existing or proposed sets of legislation, but it is important and should not be overlooked.

There may be other considerations that benefit the individual and assist the province to control costs. A living will or advance directive, for example, signed by an individual prior to discharge from the hospital might empower social services to intervene prior to a community crisis and readmit an individual to the residential care facility of his or her choice. In this way, persons with predictable cyclic patterns of hospitalization and recovery could make decisions for themselves when they are well that they may not be able to make during periods of breakdown.

Under the previous government, the Ministry of Community and Social Services commissioned Ernst and Young to perform a comprehensive domiciliary hostel review. We believe it was a fair assessment, with appropriate recommendations. However, we are not aware of the study's current status. We suggest this document may be helpful in addressing the unique situation involving the GWA population living in residential care settings.

In the main, we believe Bill 19 is a productive and positive step forward. We hope our comments have been helpful, and we thank you for this opportunity to present to the committee today.

**Mr Ramsay:** Thank you very much for your presentation. I wanted to ask you to clarify a little more the area of rights advice. You say you support the government's position to delete the rights advice from the act, yet you go on to say that people familiar with residential care



settings will know it's basically a matter of practice that it happens. I know you're concerned about the red tape in the existing legislation for how that rights advice has to be delivered, but would you object to having it put in the act that it's at least a requirement, though it may be delivered in a much more casual way, that the patient understand they have the ability to appeal that decision?

**Mr Porter:** I think we would agree with that. We had a problem with the formal requirement for basically an outsider to the whole treatment process to come in and interfere with its natural flow, particularly in the case of GWA post-psychiatric residents, by providing advice to people who are maybe not in the best position to handle it right at that particular time. That's why we proposed the idea of the advance directive for those people, so they could make decisions at a time more appropriate in their own lives, when they're more capable of doing that.

**Mr Ramsay:** I'm glad you agree with that, because my concern is that it may not be the standard practice everywhere. I feel that by trying to correct something that was too bureaucratic in the present legislation, government has maybe gone too far by eliminating it entirely. Especially, if people have the right to appeal, they should be notified of that.

**Mrs Boyd:** Let me clarify. Your association represents retirement and residential care facilities that are currently unregulated. Is that correct?

**Mr Porter:** That's right.

**Mrs Boyd:** Some of what you suggest suggests to me that you may be looking for some regulation in some areas. Would I be wrong in assuming that?

**Mr Porter:** For the last number of years, actually, we have proposed in our association that there be some regulation of our sector, and we presented that point of view very strongly when the discussions were under way to introduce Bill 120, which put us under the Landlord and Tenant Act and the Rent Control Act. We argued at that time that even if there was some control over our rates, which we didn't absolutely definitely object to, we would go along with that. We did not belong in the Ministry of Housing. We belonged in Community and Social Services or Health. In fact, our association has set up its own standards system and its own self-evaluation system of residences to meet that need.

**Mrs Boyd:** Was that effort in response to the Lightman report, Dr Ernie Lightman's report, which looked at unregulated residential care and found indeed that there was great evidence for the need for rights advice and for the need for advocacy for people living in those facilities? It is a report that many found shocking and I find it rather surprising, quite frankly, that we would take very seriously the notion that rights advice was not required in a setting, having read the evidence in the Lightman report. I'm amazed.

**Mr Porter:** Well, we're speaking for our association members, and we feel that right now we have a system of standards and so on in place in our own association which is well regulated and well inspected and in those facilities the staff and the administrations very much have the needs and interests of the residents in mind. We'd like to see that kind of regulation throughout the entire industry, but we don't want to have this kind of more

bureaucratic system of rights advice, which in many cases could interfere with the treatment or care plans, as a kind of halfway measure. We'd rather see that the other facilities which are not members of our association are subject to more regulation, perhaps through municipalities, if they're not willing to join our association.

**Mrs Boyd:** That was certainly Dr Lightman's finding, that some were good and some were—

**The Chair:** Thank you, Mrs Boyd. Mr Johnson.

**Mr Ron Johnson:** Mr Porter, I want to thank you for your presentation. It was certainly insightful. I want to say it's encouraging to see that you support the government in its move to repeal the Advocacy Act. To steal a line from my colleague Mr Marchese, you're not the first person to come forward with that idea. We've had a number of people who—

**Mr Marchese:** Two more people who did have said—

**Mr Ron Johnson:** There have been a number of people who have come forward and expressed a number of different ways that advocacy service can be provided more at the grass-roots level and that advocacy service isn't about a bureaucracy. Advocacy service is about providing grass-roots service to people who need it, and it's encouraging to see that you recognize that as well.

I guess where I'm going with this is, I want to get some ideas from you, if you have any suggestions, on ways we can sort of tap into a lot of the volunteer organizations that are already there, ways we can possibly organize that so there's a concentrated effort to provide organized advocacy service, and of course the government to play a role, whether that be in training or otherwise. I just want to get some feedback from you on that.

**Mr Porter:** It's something I haven't thought about in a great deal of detail. I think members of our association do support the concept of vulnerable individuals having somebody they can turn to when that's necessary, and I think if we could involve some existing volunteer groups, that would be great, but we don't want to have this kind of a system where people can come in and almost cause trouble. It's set up so that that's possible, so that somebody can walk in and start going around fishing for issues that may not exist, but if you talk about them long enough, maybe you can make them exist.

**The Chair:** Thank you very much, Mr Porter. The time is up and we thank you for your presentation.  
1440

#### CANADIAN MENTAL HEALTH ASSOCIATION, OTTAWA-CARLETON BRANCH

**The Chair:** Our next submission is from the Canadian Mental Health Association, Heather Smith-Fowler. Welcome. If you could identify yourselves for the purposes of Hansard, you then have one half-hour, including questions.

**Interjection:** Twenty minutes.

**The Chair:** Or 20 minutes, sorry.

**Ms Joanne Lowe:** Gee, I thought we were getting another 10 minutes there.

**The Chair:** No, unfortunately not. We'll be walking to London instead of flying if that happens.

**Ms Heather Smith-Fowler:** My name is Heather Smith-Fowler. I am a member of the board of directors



of the Ottawa-Carleton branch of the Canadian Mental Health Association. I am also chair of the Community Housing Resources Coalition, which is a coalition of community members to try to expand and help better coordinate the housing stock in Ottawa-Carleton and supports for people with mental illness. I am also a family member of somebody who has been diagnosed with mental illness.

**Ms Lowe:** I'm Joanne Lowe and I'm the executive director of the Canadian Mental Health Association, Ottawa-Carleton branch.

**Ms Smith-Fowler:** As you may know, CMHA is a non-profit organization involved in the planning and delivery of services for people with a serious mental health disability. It's directed by a community board and partnered with members of the community, including consumer survivors, family members, other community agencies, government representatives and planning bodies. Our focus here today is on the implications of Bill 19 and how changes to the Substitute Decisions Act and Consent to Treatment Act and the revoking of the Advocacy Act will have an impact upon the lives of people who experience a serious mental illness, such as depression, schizophrenia and manic depression.

We at CMHA believe in the rights of self-determination and choice, and we believe that people who experience mental illness and other types of disability have the same rights as those who do not, and we believe that these rights need to be respected by all people at all times.

But we can't assume that the rights that are provided to all people are respected at all times. There are some people who, through no fault of their own, are unable to insist that their rights be respected. Children, people who are disabled, the elderly, basically anyone who in any way relies on another person or a group of people for care, support or financial assistance can be considered vulnerable, and these relationships have a power imbalance. There must be a system that ensures that trust and rights are not violated.

While in most cases the person upon whom an individual depends for care and support is respectful of rights, we know, there's documented evidence of tragic abuse and rights violations. On the most tragic end of this continuum is the case of Joseph Kendall, who was a resident of a care home in Orillia, Ontario, and who died in 1987. As you know, it was the coroner's inquest into his death, which disclosed neglect, which led to the Lightman commission, which in turn studied the conditions of care homes across Ontario.

The Advocacy Commission was established to protect vulnerable individuals from these types of abuse, neglect and rights violations. Their third-party, objective role is intended to ensure accountability and the safety and security of the more vulnerable people in our community.

The government has stated concern that this commission is bureaucratic and intrusive and that advocates could enter institutions and hospitals and even private homes without a warrant and at virtually any hour of the day or night and that the members of the commission had the power to examine records belonging to an institution, in some cases without the consent of the people they related to.

We believe that the right of entry and the right to access a facility's records are necessary powers in the rare event that an institution attempts to prevent access of a rights adviser to a patient or client. The rationale that the current government is using to revoke the Advocacy Act and disband the Advocacy Commission is one which hinges on a belief in the protection of privacy and self-determination, but in this case it's not of an individual but of an institution and the self-determination of a professional body. One of the aims of the Advocacy Commission has been to protect privacy and self-determination of the individual. We don't believe that it was ever the intent of the Advocacy Act to override individual rights, but to enable an individual to exercise them.

In terms of the role of rights advisers, we like to think that, as professionals, it's our professionalism that makes us objective, but it doesn't. There's a common belief that health care professionals are objective, and they're not—we're not. Each person is subject to their profession, their way of viewing the world, their work, their clients or patients, and it makes them inappropriate to be third-party rights advisers.

There's also a notion that the process of providing rights information and advocacy is confrontational and adversarial, but in most cases, advocates have tried to avoid confrontation and attempt to work cooperatively with family, friends and service providers.

We believe that clients, in working with their health and social service workers, their family and their friends, intuitively know what's best for themselves, even though it may seem to be in conflict with a profession's values and belief system. We may not agree as professionals with their choices, but they have a right to these choices. We may not even agree with them as family members, and we have the responsibility to support these choices. It's critical that we listen to people and respect their decisions regarding their own treatment and care.

With the adoption of Bill 19 as it currently stands, there will no longer exist a truly neutral third party that can do individual case, systems and rights advocacy for vulnerable individuals. The proposed amendments which Bill 19 brings to the Mental Health Act will permit the minister or psychiatric facility to designate rights advisers to provide rights advice in psychiatric facilities.

But instead of advocates providing rights advice, this rights information will be provided in specified situations by specific persons working within the system, and there's great danger of subjectivity and conflict of interest. There's also the great danger that the values and beliefs and needs of the patient will be lost. This is a common and concerning experience of psychiatric patients, as I think you've already heard today.

Bill 19 must be amended to guarantee a vulnerable person's rights and access to a third-party objective person to work on their behalf.

**Ms Lowe:** I'd like to spend some time speaking to the Substitute Decisions Act. Subsection 24(1) of the current Substitute Decisions Act provides that a person who provides care to an incapable person cannot be appointed his or her guardian of property. Exceptions to this are included in subsection 24(2). Bill 19 will amend this section to allow a person who is providing care to also become a

court-appointed guardian of property "if the court is satisfied that there is no other suitable person who is available and willing to be appointed." This amendment could permit a caregiver to also be guardian of a person's property. This provision could lead to potential abuse by caregivers who could, under the guise of providing care services, appropriate an incapable person's property.

Also of concern to us is subsection 50(2.2), which removes the ability of a patient who has previously granted the power of attorney for personal care to then be able to revoke this power of attorney once the power has come into effect.

Similarly, we see the provision which waives the grantor's right to apply to the Consent and Capacity Board for a review of a finding of incapacity as being a denial of a person's right to due and fair process.

Although a person may be incapable of making informed decisions when their symptoms of the mental illness are most acute, there will be many times when their symptoms are being managed or have alleviated to the degree that they are quite capable of informed decision-making. The cyclical or episodic nature of mental illness demands that a person have the right to appeal decisions of incapacity.

Bill 19's removal of other aspects of the Substitute Decisions Act also concern us, for example, the deletion of subsection 66(12), which prohibits the use of electroshock as aversive conditioning without consent, and the amendments to subsection 66(10), which delete the requirement that the guardian not use or consent to the use of restraint or confinement unless this was consistent with the guardianship plan. Such amendments expose the vulnerable person to horrible abuse.

#### 1450

I'd like to speak to the Health Care Consent Act. This act was created to protect the vulnerable person's right of informed choice and to protect those who are assessed as being mentally incapable of making informed choice regarding treatment. The Health Care Consent Act, however, focuses more on the rights and protection of health care providers than on clients' rights.

The Health Care Consent Act, in subsection 2(1), excludes certain things from treatment such as assessment of capacity and routine care that is not a risk to client or patient. A health care professional is no longer required to ask for or receive consent for these aspects of treatment. Nor is a practitioner required to ask for or receive consent for an adjustment of variation in treatment if that practitioner deems the adjustment poses no risk to the patient. In this manner, Bill 19 merely strengthens the power of the health system and professional, rather than the powers of the patient or the individual.

The Consent to Treatment Act allowed professionals the right to provide treatment in situations of emergency; that is, when a patient is experiencing severe suffering. The Health Care Consent Act, in subsection 23(1), broadens this allowance to include when a patient is deemed to be apparently experiencing severe suffering, in the opinion of the professional.

Where are the criteria for emergency? Our concern is that behaviours which are symptoms of a mental illness

may be seen as problematic or inappropriate to a health practitioner, and be assessed by a health practitioner as rendering a patient incapable of decision-making. We are very concerned that treatment may then be given to control these symptoms with the justification that it was an emergency.

Bill 19, in section 23, also gives the right to a health practitioner to treat in an emergency when a person is capable of providing or refusing consent but when communication between the health practitioner and a person to get consent can't take place because of the person's disability or language barrier. Section 23 states that reasonable steps must be taken to find practical means of enabling the communication to occur.

With the cuts already being made in the health and social services sector by this government, and the resulting tremendous pressure on professionals to be providing more and more services with less resources than ever, what is reasonable and practical can barely meet the basic needs. Special or minority needs, such as francophone staff or cultural interpreters, are very rarely met. We are very concerned that in these cases rights will be violated. We believe that the purpose of the legislation should be to protect minority rights and needs.

While recognizing that genuine situations exist when treatment must be provided immediately, the vagueness of the words "emergency" and "reasonable steps" and "practical means" may result in the creation of many loopholes for rationalizing the denial of rights. This section must state clearly that it is the professional's responsibility to ensure and demonstrate that all possible means of communication are explored prior to any treatment being given.

**Ms Smith-Fowler:** In terms of determining capacity, in Bill 19 it's not clear what the specific procedures or criteria are for determining the capacity of a person to provide informed consent. Previously, a person's incapacity was determined by someone experienced as an assessor of capacity, but the current bill seems to leave this determination to clinical practice.

In our view, this is even more disturbing when the Consent and Capacity Board, which reviews appeals, does not require in its composition anyone with expertise in evaluating capacity, except when it is a panel of one, when that review board must have relevant experience but not necessarily expertise. While the amendment to the Mental Health Act states that to deal with applications under this section the board must sit in panels of three or five, it's unclear as to when the individual will be afforded a panel of three or five or one.

We believe that the Consent and Capacity Board should always be composed of a minimum of three objective persons with relevant background and experience. We recognize that efficiency and timeliness are critical in health care, but we urge this standing committee to provide a fair objective process that ensures that individual rights are not put at the mercy of what is convenient to the system.

In terms of the role of family, we at CMHA strongly value the role of family members in the lives of people with a mental illness. We see daily the commitment and



caring these family members provide to their loved ones. We hear of and know and witness the struggles, the grief and joys that parents, brothers and sisters and children of people who experience mental illness, what they go through. We believe that these family members do have the best interests of their kin at heart.

We also recognize, however, that what a child, a parent or a sibling wants, or believes is best for their relative, may not be what that relative wants. A family relationship should never nullify accountability to the individual. We feel that Bill 19 weakens the accountability of family members, since a formal statement will no longer be required before the decision is made on behalf of their so-called mentally incapable relatives.

According to subsection 27(6) of the bill, health practitioners will be permitted to rely on assertions by family members, or anyone else who gives or refuses consent to treatment on an incapable person's behalf, and to rely on the accuracy of these assertions without formal statements being offered by these family members.

By way of conclusion, the CMHA, Ottawa-Carleton branch, strongly urges this committee to revisit the fundamental principles upon which the Consent to Treatment Act, the Substitute Decisions Act and the Advocacy Act were inspired and built. These pieces of legislation arose from the documented and unfortunate need in our province for the rights of vulnerable individuals, including people with a mental illness, to be protected from professional and system abuse, neglect and violation. It is the rights of these individuals that need support. Legislation must recognize the tremendous power imbalance that exists in an institution, especially when a person is deemed incapable. Legislation should serve to create an environment which remedies this power imbalance.

The repeal of the Advocacy Act, and amendments to the Substitute Decisions Act and the Consent to Treatment Act are being rationalized as correcting system inefficiency and treatment delay. The absence of the Advocacy Act means that the vulnerable will remain vulnerable, and the replacement of the Consent to Treatment Act with the Health Care Consent Act makes it easier by law for people's rights to receive or refuse treatment, to appeal decisions regarding their own capacity to decide, and even to receive information about their rights and opinions and options to be dismissed.

We believe that the efficiencies which the government is striving towards can exist within a system of checks and balances that ensure protection of rights.

We don't want to create a community that does not allow health care practitioners to do the jobs they're trained to do. We don't want the quality of care to be compromised. But what we do want is to ensure that the understanding of what constitutes care includes caring about a person's right to choice and self-determination.

Thank you for your time.

**Mr Marchese:** Thank you very much for your presentation. I think your conclusion is perfect. You're not against efficiencies. What you have talked about and everything you've said here is that there needs to be checks and balances, particularly for those people who suffer system abuse, neglect and violation.

I didn't have time to ask you, but I was going to say that the stated purposes of the bill really are contradicted by the content, because when they say "to provide rules with respect to consent to treatment that apply consistently in all settings, to enhance the autonomy of persons and to promote communication and understanding between health practitioners and patients," it's really not happening when you look at all the things that you've said; is that true?

**Ms Lowe:** Yes.

**Ms Smith-Fowler:** That's our concern.

**Mr Parker:** Thank you very much for your presentation. In the minute available to me, I just want to make one point that I hope will give you some comfort. In the second paragraph of page 4 you express concern regarding section 50(2)2 which, in your submission, removes the ability of a patient who had previously granted a power of attorney for personal care to then be able to revoke the power of attorney.

What I want to assure you is, that section does not have that effect. The existing provisions for revoking a power of attorney remain in effect. What this particular provision does, however, is it gives the grantor the option to make the power of attorney survive any subsequent expression of desire to revoke it if he suffers from a particular case—the type of thing we've been talking about, where somebody slips in and out of a mental condition. He has the option to say up front, "If I subsequently lose my faculties and I insist on revoking my power of attorney, I want you to ignore that instruction."

**Mr Ramsay:** Thank you very much for your presentation. Looking back at the couple of paragraphs on determining capacity, it's certainly shocking to me and to my colleagues that as we do talk about the Consent and Capacity Board and the appeal mechanism that gives, we're still quite shocked that the patient, once a finding has been rendered, does not have to be told of his or her rights.

1500

**Mrs Caplan:** Or the finding.

**Mr Ramsay:** Or the finding itself. We think that really has to be in the act. I'm glad you touched upon that in your summary.

**The Chair:** I thank you for your presentation. Your time is up.

**Mrs Boyd:** Mr Chair, on a point of order: I was just wondering if you could ask our researcher, Susan, to provide for the members of the committee the recommendations that flow out of the report of Dr Ernie S. Lightman, A Community of Interests, the report of the Commission of Inquiry into Unregulated Residential Accommodation. I would like to ask that we all read the whole report, but it's very large and I don't think that's very realistic. But the recommendations certainly which came out in 1992 were very important in terms of some of the issues that have been raised.

**The Chair:** Is there any objection to that? No? Sounds like a good idea to me, too. Thank you. We'll get that.

**Mrs Caplan:** Also, while we're at it, the other report that was mentioned here, the Ernst and Young—

**Mrs Boyd:** Yes, the Ernst and Young domiciliary hospital report.

**Mrs Caplan:** —if there is an executive summary to that, and also if the government's prepared to let us know what the status of that is. Since it was raised at committee it would be helpful to have an answer for them.

**The Chair:** Perhaps you could raise that with Mr Parker here. Now, we're taking up Mr Tennant's time, and that is not fair to him.

STEVE TENNANT

**The Chair:** The next submission will be the Tayside Community Options, Steve Tennant, board member.

**Mr Steve Tennant:** Thank you. I'll apologize firstly. We're all trying to deal here with mechanisms, and my mechanism, the photocopier, died last night and so I was only able to provide 10 copies. In the spirit of sharing, let's do it.

Thank you for the opportunity of speaking to you today about my concerns regarding Bill 19.

It will be four years ago tomorrow that I first spoke to the standing committee on advocacy, substitute decisions and consent to treatment. It seems incredible to me that after all this time the number of investigations, hearings, reports, writing of bills, parliamentary debate and the passing of same, I am here again to try to get across the need of accessible, consistent, legislated advocacy for all vulnerable people in this province.

This all began because it was realized there is a segment of our population that is at risk of not having their rights to the dignity of personal choice respected in any multitude of scenarios, of falling through the cracks, of being victimized.

Governments may change, but the needs of these people do not go away. They may not be a segment of the population that is going to sway an election, so there are no big votes to be won or lost here, just morals, scruples, principles and ethics. There is a statement roughly interpreted that says, "Society is judged on how it supports its least able." Given this, how will we be judged when we take away the Advocacy Act, replacing it with nothing more than what was there previously, the same big cracks for people to fall through that are getting even bigger with government cutbacks to social infrastructure?

From all the reports that were completed prior to the decision on the current Advocacy Act, notably the late Father Sean O'Sullivan's report, *You've Got a Friend—A Review of Advocacy in Ontario*, and the Fram report by Mr Stephen Fram, the strong message indicated was that a working, provincial advocacy system must be in place before the Substitute Decisions Act and Consent to Treatment Act were put in place. It was seen as essential to ensuring that people are not made victims of even more bureaucracy without representation or the awareness of its availability.

It's interesting that the Consent to Treatment Act and Substitute Decisions Act were seen as slowing down the medical and legal processes of the country, so have had changes made to supposedly simplify their workings. Why is it then that the resource seen as imperative to go with these acts, the Advocacy Act, has been repealed—not repaired, but repealed—with no replacement? Bureau-

cracy carries on but protection, the original intent of all this, falls by the wayside. Please do not tell me this is part of the Common Sense Revolution.

The adult protective service program, commonly known as APS, was originated by the Conservative government as a proven response to guardianship way back in 1974, and has grown to over 150 workers across this province. We provide advocacy and case management for adults with developmental disabilities. APS is seen by our overseeing body, the Ministry of Community and Social Services, as a cost-effective program. We have indicated through our provincial organization, the Adult Protective Service Association of Ontario, to MCSS for years that we need to have some problems with service delivery for our clients corrected. These problems have also been raised on the floor of the provincial Legislature. Some are sponsorship conflict of interest, lack of legislated standardization, to name a few. Yet, to date there has been no response to our requests.

Meanwhile, this already existing program has proven itself, already provides advocacy as its mandate, but is being denied the opportunity of correcting its problems to more effectively work to support the adult developmentally disabled across this vast province. Even now there are areas of the province that have had the APS program discontinued and other areas that are suggesting placing the program with service-providing sponsors, clearly a conflict of interest. How also do we advocate for our clients with the Ministry of Community and Social Services, the hand that actually feeds us? Again it's a conflict of interest, but is this common sense?

I'm not suggesting our program is the total answer to the advocacy question. In attempting to support our specific population now we have waiting lists, and with cutbacks to our community supports they are getting longer each day. But with improvements to the program indicated earlier, the APS program could provide advocacy for the large segment of the vulnerable population we know locally as developmentally delayed.

It is interesting that the doctors and lawyers who have complained about being hampered by the acts have been able to have proposed changes made to the Substitute Decisions Act and Consent to Treatment Act less than two years after their enactment. Compare that to the APSWs who have been working within the system for 22 years and have been unable to get recognized and change fundamental problems that impair our ability to advocate for vulnerable adults of this province. There appears to be an imbalance in whose rights are being recognized and dealt with.

I have worked in several roles supporting people with developmental disabilities in many areas of the province for 20 years. During this time I have observed most that we forget that it takes time for someone to open himself up to you and trust you with his thoughts. It takes time to develop a rapport with someone and gain that trust so that you know what he may need your advocacy support in. The adults we work with have been so well-meaningly overprotected, they often lack the experience of making their own choices to the degree that they are able. Many would have been capable of directing their own lives, but now are dependent on the system for support, as they



lack the confidence and self-esteem to follow their dreams and their desires. The more delayed someone may be, the longer it sometimes takes to understand where he is coming from. APSWs are a voluntary program in that we can only work with someone who wants our help. Yet often, if you've never made choices for yourself, why would you ever think of wanting an advocate? Being known in the community, being around programs and taking the time to talk with them can help, but it all takes time.

Ontario is incredibly vast and diversified, but when you look at a map, the majority of it is rural. I grew up in Toronto but I've been working as an APSW in Lanark county for 14 years and have come to appreciate the benefits of what we call community. Because I am raising my family and living in a community my clients live in, we see one another in the stores, downtown, at the park or recreational events. As a result, I know them and they are familiar with me, so the process of advocacy for and with them is often simplified. Families don't see me as a threat because they know me as part of the community.

#### 1510

I've described this because I feel we've lost what this is all about: supporting and empowering vulnerable people. How can someone in Toronto or Ottawa advocate for one of my clients in Perth?

Let me share with you an example. An 18-year-old young man lives with his mother and her boyfriend. He is physically handicapped, has spastic movement, uses a wheelchair for mobility and has limited ability to direct his personal care. He is heard by a neighbour, screaming, "Stop hitting me, Mother!" The neighbour calls the OPP, as this is in a rural setting, who upon investigation found the mother admitting that he had chased her and grabbed her, so she started hitting him. Upon further investigation, speaking to the boyfriend and the young man's brother who sometimes lived there, the OPP were told that this was probably not a safe place for this young man to be staying. Mother stated she needed him there for his disability pension cheque. Service providers in the community reported that this same mother had threatened suicide previously if her son was not placed elsewhere for extended periods of time, and yet, when planning was put in place to have him moved elsewhere, she refused.

As a result, the police temporarily suggested he be placed in a relief bed site they sometimes used and they called the APS program. The OPP did not see the use in laying charges, as it was the son's word, which he was not able to present, against hers. But they realized there was a problem, so I made them aware of the new urgent investigations unit, UIU, of the public guardian and trustee's office. The OPP called and reported the case to them.

I followed this up with the UIU office, making them aware of my previous involvement. I felt this young man required a guardian, as he was unable to protect himself from the physical and financial abuse that his mother admitted to. Other support workers in the area supported my request. It remains unclear what the UIU office was willing to do to protect this man. His mother began challenging and coerced the UIU worker to allow her to keep approximately \$100 of her son's \$700 monthly

cheque, giving the home where he was staying the rest of it to buy clothes for school. She in fact reneged on this promise and kept everything except \$10, but no recrimination came from the UIU office.

Time dragged on, and when I requested who should sign school forms, it was indicated to me by the UIU worker that I should do a hand-over-hand X—assist him in making an X—with this young man, even though I knew he was not able to give informed consent. I refused, indicating to both the UIU worker and the supervisor that this was illegal. Even after letters of support from the director of social services, who knew the case, and the Ministry of Community and Social Services area program supervisor, no one came to visit either the young man or the mother, and without any further consultation he was returned to his mother's care. So far he has stayed in the relief home, but she has refused counselling, so he still remains potentially quite vulnerable.

I attempted to approach the Ombudsman's office on this young man's behalf, as I did not feel he was being properly represented at the UIU office, but was told by the Ombudsman's office that since this young man could not give me consent to speak to them, they could not take my statement of concern. I explained that he was mentally unable and this was why I was asking for a guardian to be put in place for him. This did not seem to matter. My complaint was not heard. So again this vulnerable young man was refused the support of the mechanisms actually put in place to protect people like him. That's quite a system.

How does this young man get assistance from the big bureaucracy? They made no attempts to visit him and get to know him or his situation. Yet, even though I knew the case well and had community approval for what I was requesting, I feel my role as an advocate under the APS program was not recognized or respected, so advocacy for this young man was compromised, in fact, by the system.

By giving workers like APSWs the tools to work in their own communities, much of the local advocacy could be completed avoiding the faceless bureaucracy so often unnecessary.

There are some amazing families doing fabulous jobs at supporting their vulnerable individuals, but let us realize—and I think you've heard this a lot today—that not all of them are wonderful. For some families, the vulnerable person is a means to increase their income by the person's disability cheque, with little or no interest in what this person may wish to do or where they might wish to live or hang out. With some families, even the thought of suggesting the money from the individual's disability cheque should go to assist with paying for the wants and desires of that person is seen as ridiculous. Just living with them is seen as a privilege.

In this situation, how does the individual have his or her rights respected when the one calling the shots is the one putting the food on the table and is family? Studies around abuse show the most vulnerable are the most likely to be exploited, often by family, friends and neighbours.

I describe this because there needs to be an access and review mechanism put in place to observe how families

or caregivers are supporting and respecting their relative's or resident's rights, not as an invasion of their privacy but, if anything, an affirmation that they are doing what is best for that vulnerable person. These are not easy choices, but ones that must be responded to for the best interests of the vulnerable persons who cannot speak for themselves or may not be given the chance.

It has been suggested that volunteers can assist with advocating for individuals, and this in its ideal concept sounds quite possible. In fact, though, I have seen only rare ones actually work. I say "rare" because this is what they are. If you talk to the volunteer segment of our communities, you will find volunteers are becoming fewer and more particular in what they do. I was on the board of our county Big Brothers/Big Sisters organization for more than 10 years, while also sitting on the provincial Big Brothers board, and from these experiences find volunteers are becoming harder to lure into supporting roles. Some of those in need of advocates are extremely hard to work with, so people who find rewarding experiences in this are few and far between. Training and liability issues are becoming larger concerns, as well as the lack of accountability for volunteers.

I have been trying through many channels to secure a person to visit a client I have who has no family and has required total care for six years now, and have yet to have any success. I will keep trying, but please understand this is difficult.

In summary, please remember these points:

(1) Society is judged on how we support our least able.  
 (2) It's one thing to remove the Advocacy Act because it is not working, but it was put in place for a reason and the reason is not going away, so other responses must be found to fill those gaps.

(3) It was previously recognized that the Advocacy Act must be in place before the Substitute Decisions Act and the Consent to Treatment Act. Why is this now being disregarded?

(4) The APS program is an existing, cost-effective way of assisting with this response. If you can make changes as needed to these other acts, you can also legislate the necessary changes to the APS program to better respond to its mandate, advocacy.

(5) Recognize that true advocacy takes time, and respect this in any of your planning. True advocacy takes time.

(6) Remember that the majority of this province is rural and has difficulty relating to urban bureaucracy.

(7) With all due respect, recognize there are some less than honourable families, so expecting everything positive from expanding their abilities to be involved may not be in the person's best interests.

(8) The most vulnerable are the most likely to be exploited, and often are by family, friends and neighbours.

(9) Volunteer involvement sounds great, but the reality is that to expect much from this is being very unrealistic.

(10) In conclusion, I recognize these are difficult times for you as government representatives to maintain fiscal responsibility. I do pray, though, that you do not see this as a dollars-and-cents issue because the lives of vulnerable people who deserve our support, in this caring com-

munity, and of our caring community, depend on your understanding and your ability to respond and cooperate. Please don't let them down. I thank you for your time.

**The Chair:** I thank you for your thoughtful submission, Mr Tennant. Your timing is impeccable; you used exactly your 20 minutes, so I thank you very much.  
 1520

#### KEN HRANCHUK

**The Chair:** Dr Ken Hranchuk. Welcome, doctor. You have exactly 20 minutes, including questions.

**Dr Ken Hranchuk:** My presentation today closely reflects the contents of my written brief. I have an overriding concern that all persons in our province have the right to receive the most effective treatment, regardless of their level of functioning, either physical or mental.

Specifically my support for the removal of section 66 of Bill 108 goes beyond allowing the most effective treatment for life-threatening, self-injurious behaviours in persons who cannot consent to such treatment. If that section were to become law, it is quite possible that other effective treatments could, in the future, also be disallowed for those unable to consent to treatment.

For example, I work with numerous children who demonstrate a variety of self-injurious behaviours across the eastern Ontario region. My therapeutic interventions include all the positive non-aversive procedures available to me as a professional in the field. However, on occasion, purely positive interventions are not sufficiently effective in decreasing some intense high-frequency, self-injurious behaviours.

I'm not sure the general population is aware that there are individuals in our society who demonstrate such severe self-injurious behaviours that they are life-threatening. In my personal caseload, I've dealt with young children who eye-poke; they'll shove their finger up their eye socket to the point where retinal damage is of concern. I've worked with many children who severely ear-slap, resulting in mushrooming of their ears and damage to the tissue around the ears and resultant infections.

I've worked with many children who are self-biters, a very serious condition that results in the breakage of the skin and is also dangerous in terms of infectious diseases. I've also worked with many children who are head-bangers. I hate to use that term but that's the best way to describe it, and there can't be anything more disturbing than to see a young child who looks as normal as most children embarking in such severe behavioural patterns.

What we do know is that early intervention in these children, across environments where these behaviours occur, can prevent a life-long disorder from disrupting that young person's life. The treatment personnel and trained parent therapists I work with have found that minimal physical restraint can be used effectively in young children with serious self-injurious behaviours, and it can result in the elimination and the continued reduction and maintenance of that elimination over time.

Minimal physical restraint is a simple procedure whereby a parent or a trained therapist will take a young child's hands and hold them to his side and wait until he's calm and then release him. Then, of course, at that



point there would be the commencement of numerous positive training programs that would kick in to teach the child that he or she can get attention without having to be self-injurious.

If Bill 108 had been implemented, it could have set a precedent that might have led to things like minimal physical restraint also being disallowed in the future by preventing parents from consenting to treatment for their children who are unable to do so. This is not an exaggeration. There are a number of states in the United States that now have passed laws preventing such things as minimal physical restraint. The problem with that is that there are no alternatives presented. Of course, many people who are advocating against these techniques have the children's self-interest in mind.

There's no question that our field is a controversial one and that many people, in advocating against these techniques, are doing so because of their love for their children, but they must be responsible in making sure that the families and the therapists who are confronted with these severe behaviours have alternatives. If not, we have to look to what is most effective at this point in time.

If that were to happen, I can assure you I know many parents who would not allow their children to continue to embark on serious self-injury and would employ minimal physical restraint procedures if necessary in their home or whatever. That would mean they would be breaking the law and I think that's something serious to look at.

A related concern of mine is that people with developmental delays and persons with autism are not protected from interventions that are clearly scientifically proven to be ineffective. This is not an issue today, I don't think, but I do believe it's something that should be considered as also potentially intrusive or aversive. I'll give you a good example of that.

For about the past six or seven years, a procedure known as facilitated communication has been employed with this population. This is a technique whereby a facilitator, a so-called helper, takes the individual's hand and guides the hand and the consequence of that is that the target person now has some control of some sort and can spell out words on an alphabet. As of today, there are upwards of 25 soundly designed experimental pieces of research showing clearly that it is the facilitator who's doing the communicating. There has been no research yet to indicate why it's the facilitator. It wouldn't appear that people would intentionally do such a thing to a person who is unable to speak. However, that still has to be determined.

This is still going on and that means there now are people out in our society who have received this form of communication, if we can call it that, for four or five years. I don't know if you have read recently in the Toronto Sun of a case where a family was put through extreme stress, a costly process, and ended up coming forth with an \$8.5-million lawsuit against a variety of people, including educators, police forces and others, and that particular case was settled out of court.

When we look at that, there are many other examples of people who are subjecting our developmentally delayed and autistic population to unfounded treatments for extended periods of time. If a young man has been

receiving facilitated communication, or a young child has been receiving that intervention for four or five years, that has serious implications.

We know very clearly that the earlier the intervention in that particular population, the more likely we'll be able to perhaps reach some sense of normalcy, if not normalcy itself in some rare cases. That also means that during that time, that person has not received effective, scientifically sound treatment. I, in my opinion, consider that to be intrusive and potentially aversive as well. The thing about that is that the individuals cannot consent not to receive such a form of treatment.

It's unfortunate that many of our most effective treatments are somewhat intrusive and in some cases aversive. There's no question that surgery that might require amputation to save a person's life is extremely aversive to that person. Drug treatments for physical and mental problems have serious side-effects in some cases that can lead to permanent physical damage in people.

Defibrillators are used in cardiac arrest. They generate high, intense voltage of electricity in order to save a person. Faradaic stimulation, applied effectively with well-controlled standards of practice, has been shown to be effective in reducing serious self-injury. Electroconvulsive therapy, which has as its intent degeneration of a convulsion in a person in order to treat depression, is acceptable in our society. Interestingly enough about electroconvulsive therapy, people's rights can be taken away from them through the Mental Health Act in order for such treatment to be applied.

My last point is that these interventions are default technologies. This is a term that comes from my field of applied behaviour analysis, because we're so overly concerned about what we have to do in some cases to prevent life-threatening behavioural patterns or serious tissue damage or bone breakage.

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A default technology exists because there are no other technologies or therapeutic interventions at this point in time in our history that are effective enough to reduce the problem. We have to look at that seriously. We must continue to research both experimentally and applied in every way possible that we can so that we don't have to use default technologies. If we found ways of preventing physical disease at early onset, we wouldn't have to do things like remove lungs because of smokers. If we could find effective ways of identifying manners of reducing self-injury in young children at an early age that were rapid and non-aversive, then we wouldn't have to deal with situations such as the ones I'm sure you're familiar with in Ontario at this time at Southwestern Regional Centre.

I don't have any other points. I'm open to any questions and I'll try to be as informative as I can in assisting you in maintaining your stance with Bill 108.

**Mrs Caplan:** Do you believe there should be any regulation or standards applied to the usage of aversive therapies?

**Dr Hranchuk:** Oh, absolutely. I would hazard to say that I think the program at Southwestern Regional Centre is better controlled than any other program in Ontario.

**Mrs Caplan:** I agree with you and I think there are those standards in the Community and Social Services Facilities, and I know that Southwestern Regional's the only place where faradaic stimulation is even permitted under the Comsoc facilities. As I read this legislation, faradaic stimulation, other aversion therapies dealing with shock therapy, but certainly shock therapy, as it's called, faradaic stimulation, would be permitted in any office of anyone who was under the Regulated Health Professions Act or in fact, as I read it, anyone who felt they were providing treatment within the context of this legislation.

**Dr Hranchuk:** That should be corrected, because I certainly, as a professional psychologist trained in this field and on occasion having to use mildly aversive strategies like restraint, would not embark upon utilizing faradaic stimulation.

**Mrs Caplan:** Would you be comfortable if there was a clear restriction in this legislation that it be within a Comsoc facility, for example, or that we find some way of making sure that our psychologists could not provide this in their offices?

**Dr Hranchuk:** I would highly support that.

**Mrs Caplan:** That's the concern we have, that this opens it up in a way that does not ensure it only takes place in a regulated environment. In fact, the other suggestion was that as to this shock therapy for the last-resort treatment of those individuals that you recommend, another option would be that you require approval from the Consent and Capacity Board. That's another option to control it only for those special cases.

**Dr Hranchuk:** I'm a member of the board of directors of the association for behaviour analysis. I'm not speaking on behalf of that organization, but I can tell you that part of our concern is the regulation of the application of any behavioural procedures. Behavioural analysis has been misused, not necessarily by behaviourists but by a variety of people out there who feel they can write little recipes and proceed and alter human behaviour without any sense of responsibility. I'm part of a committee that's specifically addressing standards of practice, what is applied behaviour analysis and who can do it. So we're ahead of you in that sense, because as professionals we are very concerned.

**Mrs Boyd:** You premised a lot of what you said on the fear that having this prohibition in the act as it was in the original act would lead to other prohibitions. I'm sure if people did not understand exactly what was involved here, they would get very confused around the kinds of things you were saying. No one was ever suggesting that the kind of mild restraint you say you say you would use—you said very clearly you yourself would not use faradaic stimulation.

**Dr Hranchuk:** Right. That doesn't mean I wouldn't refer someone to that program.

**Mrs Boyd:** Part of the problem that certainly we had when we put the original act into place was that there were all sorts of presentations to us about how this as a method ought to be expanded, that it ought to be available anywhere, that this worked and therefore it ought to be available. This is a real problem, because you're quite right, there are parents who, faced with the very serious difficulties that some of their children have, would accept

almost anything as relief. It was certainly our concern that this was not necessarily in the best interests of the children, that the kinds of methods you have talked about using might not necessarily be used first, because they don't work as quickly; it takes time to change that behaviour.

**Dr Hranchuk:** I can't speak to who it was who was suggesting that it be expanded. However, I can assure you that as behavioural analysts, we're not seeking out people with severe self-injury. There's no consideration I'm aware of whereby somebody is advertising that we have this program. We're sitting back as responsible professionals servicing those who have come from other places and environments where that service, or whatever the intervention was, was ineffective.

**Mrs Boyd:** The reality was that in fact the suggestion was made on the part of the researchers cum treatment experts at Southwestern Regional that this ought to be in much more widespread use, that the restriction of this to four children initially—and incidentally, I would challenge your comment that this works, because I think experimentally the research shows that it works in only very, very limited cases. I think that you should know that indeed there was a desire to have this much more available and indeed a justification for its use and its quick use in terms of a quicker solution. So you need to know that.

**Dr Hranchuk:** I think the rationale for the increase of any therapeutic technique should be based upon need and scientific demonstration of effectiveness.

**Mr Ed Doyle (Wentworth East):** Thank you for coming today. I'd like to point out, first of all, that we are going to be able to restrict faradaic therapy through regulation. I don't know if you were aware of that, but that is included in the changes we're proposing. There's been some dispute in different presentations that we've had as to just how serious a shock we're receiving here. We've heard various views on this. One view was that it was no worse than walking across a carpet and touching a finger against something metallic, and we've heard other views that it could be as bad as receiving an electrical shock from a socket on a wall.

**Dr Hranchuk:** The latter view I'm not aware of. In terms of my information—and I have extensive literature on the topic and I've read it carefully—as the technology increases, the milliamperage decreases as well, so my understanding is that presently Southwestern Regional Centre uses between 3.5 milliamps and 10 milliamps for a brief one fifth of a second. Now, that's a little more of a milliamperage than is required than to generate a pace-maker. Again, I shouldn't be speaking for that program, because that's not my right, but I'm just reflecting to you what I see from what I've read in the literature, and I have no reason to doubt that literature.

**Mr Doyle:** Because we have some difficulty in trying to grasp just how bad a shock people are receiving here.

**Dr Hranchuk:** I do know it's an open-door policy, and the first opportunity I get to go there, I will subject myself to it so that I have a fuller understanding of it.

**Mr Doyle:** I was wondering just how much freedom a person would have to find out about this himself or herself.



**Dr Hranchuk:** It's an open-door policy, as I'm aware.

**Mr Doyle:** For example, if I had a child and it was recommended to me that this child be perhaps given that treatment, I would have the opportunity to try it myself?

**Dr Hranchuk:** I am aware of one case, and I do believe you've also been presented with that case, where the parent was subjected to it and did considerable research beforehand. I'm also aware of cases in the United States where there have been legal ramifications because parents weren't informed that this was the most effective treatment available and their sons and daughters had gone through long periods of serious self-injury without being informed of faradaic stimulation as an option.

**The Chair:** Our time's up. Thank you, doctor.  
1540

### BROCKVILLE PSYCHIATRIC HOSPITAL PATIENT COUNCIL

**The Chair:** The Carleton Disability Awareness Centre had an emergency and their representative had to cancel out. We're proceeding to the Brockville Psychiatric Hospital Patient Council, which was slated for 4:40. Welcome.

**Ms Linda Rheume:** I'm Linda Rheume. My colleague Steve Thomas and I are here representing the Brockville Psychiatric Hospital Patient Council. It represents the interests of about 1,300 inpatients and outpatients. The hospital serves all of eastern Ontario, which has a population of approximately one million. It is the only provincially funded long-term-care facility in eastern Ontario. Both the forensic and psychogeriatric facilities in Brockville have seen growth over the last few years. The patient council is just beginning its second year of existence and is funded by the Ministry of Health. Our mandate is to improve the quality of life of patients and to do systemic advocacy.

I'll now tell you about my credentials. I am a manic depressive with a long and serious history of sexual abuse. I've been hospitalized in London, England, and three times in hospitals in Ontario. Until 1994, I was employed at a salary of \$46,000. All my experiences in hospital—when I went in, while I was working and even after I stopped working—were traumatic. There was some physical and sexual abuse. There were some life-threatening problems regarding the wrong mix of medications. On the whole, I believe in the medical model. I believe that psychiatrists have helped me and that they will continue to help me.

**Mr Steve Thomas:** I was first hospitalized in 1973 when I was 21 years old. Since then, I've been in and out of hospital. I've spent most of my adult life inside, more than half of it, and presently I'm receiving outpatient treatment at the Royal Ottawa hospital.

What is the social, economic, medical and demographic contest in which consumer-survivors find themselves? In 1996, it could not be worse, and it is unlikely to get better soon. We haven't had an increase in FBA in over four years. What causes mental illness? Is there any way to treat it at a lower cost? Psychiatrist do not have all the answers. For some disorders the cause is thought

to be a genetic predisposition or birth trauma. Triggered by stressors, such as reduction in welfare cheques, loss of work, low self-esteem, inadequate housing or homelessness, the illness blossoms.

**Ms Rheume:** The problem at the outset is not that patients have too many rights which have to be clawed back; rather, the problem is that budget-cutting and downsizing is reducing services at too fast a rate without proper consideration of all the elements and arguing among all the stakeholders. So the psychiatric bed space now is dangerously low in Ottawa and in Brockville. Many of our friends have been unable to access hospital beds in times of crisis due to bed closures. They went to emergency—these are our friends—with such things as intermittent hallucinations, suicidal ideology or the onset of uncontrollable urges to become violent with a family member. They were turned away.

**Mr Thomas:** The movement for care is to the community. But there is no money to provide or replicate the services that disappeared from the hospitals. Bill 19 is a misguided attempt to redress the problem of lack of services by restoring illegitimate powers to doctors and family members. These attempts will backfire, and homelessness and crime will inevitably increase and lead to more expenses elsewhere in the system. Long-fought-for advances in the civil rights of the mentally ill are being thrown away. It is unlikely this will occur peacefully. There will be more aggressivity on the wards and in the streets. It is ironic that in an era of disintegrating family structure, relatives, even distant ones, are being given more power. It is even more ironic that doctors will be given more powers and are absolutely absolved of any responsibility or liability in misuse of that power.

**Ms Rheume:** I have an example of misuse of power. A physician did not like Mr Harris's omnibus bill. He then decided to identify Mike and Jim, his Minister of Health, as having various behaviours and conditions which led him to report them to the justice of the peace. This caused this next step that they were to be assessed. They were ordered for assessment under the Mental Health Act. This was an abuse of the rights of Mike and Jim. This was a doctor who had a political agenda and he misused the rights of someone. This happens every day, but Mike and Jim were in the newspapers. For us, the police arrive in the restaurant, at the office—cuffs, shackles and we are taken to hospital by police car.

In an attempt to keep our 20 minutes short, although there are many issues we worry about, we'll focus on three only.

First, we disagree strongly with rescinding the positive advances that infused the Advocacy Act and Advocacy Commission. In a time when most mentally ill people in the community are in the community, and that's what the government wants us to do, why on earth would the government see fit to limit advocacy to the hospitals? This is criminal neglect of the most vulnerable in our society: the elderly, the handicapped, the mentally ill. There is no longer any bed space in the hospitals for the mentally ill. They are largely being relocated in the community, and one of the reasons is to save money.

The Advocacy Commission was a relatively inexpensive way—\$18 million a year—to ensure that these

people's rights were protected out in the community where costs would be and should be lower. However, there will be a great fallout, much more than \$18 million, because of the bill as written. The Advocacy Act was done through negotiation, not confrontation and not expensive litigation in the courts. The Advocacy Commission had an arm's-length relationship with the hospitals and residences to prevent conflict of interest. I ask you, honourable members, who is going to fulfil that role now? To suggest family members and friends is fanciful thinking. Families of the 1990s have two jobs, adult children at home or are struggling with their own problems to find work. Many families, as you must know, although we don't like to admit it, have abandoned their mentally handicapped, mentally retarded or Alzheimer's relatives.

**Mr Thomas:** Second, the lack of liability for doctors and health care practitioners for mistreatment of patients is unconscionable. In the early 1980s, a patient at Queen Street Mental Health Centre in Toronto was murdered by excessive administration of Nozinan to subdue him. In Penetanguishene, in the 1970s and 1980s, LSD was routinely administered to patients to "break down their defences," as was Scopolamine, which was used by the Gestapo during the Second World War. A litany of cruelty and abuse was perpetrated in Penetanguishene in the name of treatment. I can attest to that, if you want details.

To remove doctors' liability for treatment opens the door to abuse. I'd love to sue Penetanguishene, but it would bring back too many memories. Witness the concerns in Hamilton expressed recently on the treatment of the brain-injured at the McMaster clinic. Cruel aversion therapy was being used on young teenagers. Please remember that despite protestations and advances, psychiatry is not a science like other areas of medicine. Expert psychiatry is closer to an art. The brain is still regarded as the last frontier of medicine. There's still a long way to go to get standardized diagnostic and clinical procedures to intervene successfully in the lives of many of the mentally ill.

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**Ms Rheaume:** On the topic of "Can I try aversion therapy before it is administered to my child?" I am now investigating on behalf of the civil rights group here in Ottawa the use of pepper spray. I asked the police, "Can I use it?" They said, "No. We have a regulation. We can't give it to you."

Our third major point: A person has no rights unless he or she is made aware of them, and a psychogeriatric pre-Alzheimer's patient or an overdrugged person who is only temporarily unable should not have all their rights taken away. It's quite beyond belief that this government would see fit to eliminate the rights adviser's role, and further to say that the patients do not have to be advised of their rights.

This opens the door to civil rights abuses of the worst kind, the forcible confinement and drugging of the fragile, suffering, downtrodden, disempowered and displaced. It is just one more regressive step in the treatment of the mentally ill and it takes us back about 50 years in the legislation that we've worked so hard for.

Even criminals are advised of their rights and have habeas corpus. Unhappy relatives and patients are going to clog the courts with litigation.

Bill 19 as drafted is difficult to understand and interpret, open to very many different interpretations. Certainly I don't think I understand it as well as I could either, even with the help of a lawyer to go through it with me.

**Mr Thomas:** In conclusion, in this life health is all we have, and for the chronically ill, the physically handicapped with a mental illness, the developmentally delayed and the psychogeriatric patient, quality of life is most important. In light of everything we have said, we have four recommendations.

**Ms Rheaume:** (1) Slow down the pace of your deliberations. Consult with the customers of these health services. Talk to the developmentally delayed. Many of them can express themselves quite well. Talk to the psychiatrically handicapped. Talk to the geriatric people. Delay, please, the implementation of your legislation until you do those things.

**Mr Thomas:** (2) Make advocates independent of hospitals. Perhaps they could work for a charitable or not-for-profit organization.

**Ms Rheaume:** Or maybe you could privatize them.

(3) Mount a public awareness campaign to explain to family and patients about this new legislation. I came down on the bus today, and the man next to me turned out to be a lawyer who works for the government. His dad did his will just before the Advocacy Act came in, redid it again, and now I told him he's going to have to have his dad do his will over again. I was speaking to a very intelligent man who could understand at least that there were problems, but what about the rest of us?

**Mr Thomas:** (4) Assure all consumer-survivors that your government is committed to humane treatment and a decent quality of life for all citizens of Ontario.

Despite the lateness of the hour, we hope you will have some questions for us. Thank you for the privilege of appearing before you.

**Mr Marchese:** I want to thank you both for your presentation. Quickly, I agree with the idea that we should mount a public awareness campaign to tell families of patients about the new legislation. People need to know, and I think all governments should do that whenever a new law is passed but we tend to fail in that regard.

I agree with you and many have agreed with you that, "The patient has no rights until he or she is made aware of them," and you say, "It is quite beyond belief that this government would see fit to eliminate the rights adviser's role, and further to say to say that the patients do not have to be advised of their rights."

Most people who have come in front of this committee agree with you, and we hope that the changes will be reflected with respect to your experiences because if we don't write policies or bills based on the experiences that you are aware of, I'm not sure how meaningful those policies are.

You talk about the lack of liability for doctors, and I have to tell you a few people mention that.

**Ms Rheaume:** No financial responsibility for any treatment.



**Mr Marchese:** In Thunder Bay they said if a substitute decision-making person is liable for any breach of duty, why shouldn't doctors be as well.

**Ms Rheume:** Exactly, and it's a criminal offence, not just a civil offence. It's a criminal offence.

**Mr Marchese:** I think it's a good point that you make.

The point that a previous speaker made about society being judged on how it supports its least able is really fundamental. It's a fundamental way of looking at how society should be governed, and that was an important saying. You support that very strongly, I would imagine. Is that correct?

**Mr Thomas:** Yes, and also I take issue with the fact that the Advocacy Act is being disbanded, because all these patients are being put in the community and there's going to be no one to advocate on their behalf. You rely on family and friends, but they're in a different city or they're alienated from you or they may be dead. Usually the parents of single children are much more elderly and they don't have any time or expertise in handling their children's affairs.

**Mr Clement:** Thank you very much for your presentation and especially the four points you mentioned at the end. Certainly this committee is spending four weeks, three of which are the consultative process, to hear from people such as yourselves, and I think some more knowledgeable and experienced colleagues across the aisle remember the weeks and months and years of consultations that have been part of this seemingly never-ending debate. But I thank you for adding your points of view on it.

What I wanted to concentrate on is something that I must confess is mystifying me. I think that you speak for persons who have experienced the evil side, if I can put it that way, of governmental institutions and how they can upset, perhaps forever, a person's life. Yet you have a lot of faith in an Advocacy Act which was creating another governmental institution, taking it away from individuals in the community, and I just don't understand the reasoning.

**Ms Rheume:** If I could bring it to a personal level again, I'm a mother. I had to commit my son. He was committed as a manic-depressive because they thought it was genetic but it was drug use. I needed an adviser, an advocate, a lawyer, a friend, I don't know what. I was distraught. He was in for three months, and they made him worse, and he was dying, he was in restraints and he wouldn't eat. So from the parent's point of view, I'm not saying the advocate has to be a government person or an institution person; in fact I'm saying they shouldn't be an institution person. They could be a legislated private group.

**Mr Clement:** How far away are we from that right now, in essence?

**The Vice-Chair:** Mr Clement, I am sorry. We are going to have to move on to the Liberal caucus.

**Mrs Caplan:** An excellent presentation. Obviously your experiences were really important for the committee to hear, and I hope that the government is listening.

You raised something that really we haven't heard before, and that is just how difficult this bill is to understand. That's because the government opted to stick in

one legislation that which before was dealt with in two separate pieces of legislation. The fact that they repealed the advocacy in there is something else, but this deals with consent to treatment, now under the Health Care Consent Act, Mental Health Act amendments, changes there, and under the Substitute Decisions Act you have both power of attorney and guardianship and it has nothing to do with wills.

It's so confusing for the average person, the average family whose lives are going to be impacted by this. They pick up this bill and try to read it with the different references. All you have to do is look at a section, and I can understand why you would say that it is complicated. I'm a legislator, and I can tell you this is the kind of legislation that has an impact on people's lives. They should be able to pick up the legislation and read it and understand it.

1600

**Ms Rheume:** Elinor, can I interrupt for a minute?

**Mrs Caplan:** Sure.

**Ms Rheume:** Steve, my colleague, feels I didn't answer this question properly. He would like to talk himself.

**Mrs Caplan:** Go ahead. Use the time.

**Mr Thomas:** I thank you for that. It's very obscure, and I think there must be a lot of Conservatives who are lawyers or something. There's not many common people could understand this legislation. The references made to the Substitute Decisions Act in the Health Care Consent Act almost negate the whole purpose of the Substitute Decisions Act, and it's totally ridiculous what's been done here.

In response to—

**The Vice-Chair:** Mr Thomas, I am sorry. We are going to have move on. The 20 minutes' time has expired and to keep on schedule, we have to go to the next one.

**Ms Rheume:** We came in place of somebody else when we weren't ready. Can we just have another minute to answer this?

**The Vice-Chair:** I'm sorry. We are going to have move on. We have to keep to a very tight schedule. It wouldn't be fair to the people following you. But Mr Clement will address it outside.

**Mrs Johns:** Could I have a point of clarification? Protection from liability, section 28, is substitute decision-maker protection. I might have misunderstood that, but I thought someone said there was no protection from liability for the substitute decision-maker.

**Mrs Caplan:** For all volunteers. This act has the broadest protection from liability of any statute I've ever seen, Helen.

#### ONTARIO COLLEGE OF FAMILY PHYSICIANS

**The Vice-Chair:** Good afternoon. You will have 20 minutes for your presentation in which you may want to leave some time for some questions. You can begin any time.

**Ms Cheryl Katz:** Thank you. A hard act to follow.

I'm Cheryl Katz, executive director of the Ontario College of Family Physicians. With me is Dr Gordon Riddle, who is a director on the board of directors of the

Ontario college. He's a member of the college and provides a broad spectrum of practice of care to his patients. Dr Riddle has a large component of elderly patients in his practice and a large nursing home component of patients in his practice.

Our purpose in making this submission today was to stress the need for flexibility and ease of administration in applying this legislation. We, as a college, became involved in the Substitute Decisions Act and the Consent to Treatment Act well into the 1980s. At that time the president of the college, Dr George Miller, was a strong advocate for the need for adequate protection of the mentally ill. Since that time, we have become very involved in this process.

We've now reviewed the amendments proposed in Bill 19 and, contrary to what has been said, we actually endorse the efforts of this government. What we find in reading Bill 19 is that in essence it codifies the common law with respect to consent to treatment and attempts to streamline the process of caring for the mentally and physically ill. As I said, one of our objectives in making this submission is to reinforce the vital importance of ensuring that the delivery of health care proceeds efficiently and effectively with the minimum of unnecessary delays and unencumbered by bureaucracy and administrative inflexibility. We do believe that Bill 19 is a step in the right direction.

We were pleased to see the concept of treatment fleshed out in the Health Care Consent Act and rationalized within the context of the bill to enable initial assessment of capacity, physical exam, history taking and care providing little or no risk of harm. We do believe it is in the best interests of the health care providers and of patients that significant efforts be made to provide education to health providers, as well as to the public, to allay the fears that have arisen around the issue of providing treatment.

To that extent, we absolutely endorse what was said moments ago, that there must be efforts at public education around this piece of legislation. We believe that it is often the case that there is confusion arising around tables, pieces of legislation. A lot of the fears arising out of that confusion can be allayed by a public education process.

We were also pleased to see the protection from liability in respect of the administration of treatment done in good faith with apparently valid consent.

Under the Health Care Consent Act there is no longer a requirement for a panel of three or five members to sit for every application being heard. The chair, under that act, is now empowered to assign a member of the board to sit alone with respect to a particular application. We believe that streamlining that process is a move in the right direction. We believe it is appropriate that the act goes even further, to eliminate some of the other requirements relating to the composition of the panel such as the expertise in applications involving capacity.

But in principle, we have a problem with the whole concept of the Consent and Capacity Board. We believe, in a word, that Bill 19 doesn't go far enough in terms of streamlining. We believe the board itself should be abolished. From the perspective of cost-effective and

efficient delivery of care, we question the necessity of establishing this board at all. Experience tells us that establishment of administrative and quasi-judicial tribunals don't streamline processes, particularly where there is an unfettered right of appeal to a court which has the ultimate jurisdiction to determine questions of capacity, among other things. The decision to continue this board, albeit under a shortened name, is questionable. We recommend that the decisions regarding capacity to consent to treatment under Bill 19 be taken directly to the court to eliminate what we see as an unnecessary, time-consuming and costly middle step. In the interests of the public and the providers, it seems that with this kind of mechanism in place, the only people who are happy are the lawyers.

**Dr Gordon Riddle:** One of our biggest concerns in the past has been the case of patients suffering from serious mental illness being allowed to deteriorate because they were assumed to have had capacity to refuse treatment in the community. Formerly, no one had authority to treat these individuals until they became a serious threat to themselves or to others. With the passage of Bill 108, the Substitute Decisions Act, patients' needs could, for the first time, be met. We were pleased to see that under Bill 19, the scheme of substitute decision-maker was simplified and priorities among them streamlined.

Under this legislation, the public guardian and trustee is intended to be a substitute decision-maker of last resort. However, the need for treatment decisions can occur at any time. In caring for seriously ill patients, situations requiring a decision of the PGT do not pay homage to weekends or holidays; the PGT must be available and accessible at all times. We would strongly recommend that there be a duty roster to ensure that in such cases, a PGT is available to make the needed decisions. Time is of the essence. Availability of a PGT must be ensured. However, once accessed, the decision-making must be expeditious, with the minimum of delay. We would suggest that the process could be expedited if the office of the PGT had onsite, professionally trained health care providers. Such support could facilitate rapid decision-making by focusing issues and concepts.

At the same time, we also question the ability of case managers to operate effectively and efficiently. Once again, experience tells us that unless case managers are adequately trained and funded, this method of entry into the system can create a tremendous bottleneck. We would recommend elimination of case managers by the introduction of a streamlined approach whereby standardized forms and flexible protocols enable direct access to the public guardian and trustee in order to eliminate an unnecessary step.

We stress the need for flexibility in interpreting and implementing this legislation in the interests of providers and the public.

We applaud the repeal of the Advocacy Act as ill-conceived legislation. Health care providers enter this discipline motivated to help others and act in their best interests. The Advocacy Act assumed that vulnerable people need protection from health care workers. A new layer of bureaucracy was created in the Advocacy Act to respond to this perceived need. We endorse the repeal of



this act. Although we feel that the repeal of the Advocacy Act is good, there is still a need for protection of incapacitated persons. An agency akin to the children's aid society which health care providers and others could contact might be considered to fill that role. We have seen instances of neglect and emotional, psychological or financial abuse of patients in nursing homes by family members.

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Our recommendations:

(1) Education of public and health care providers about Bill 19 to allay concerns.

(2) Abolish the Consent and Capacity Review Board to enable decisions to be made directly by the court, thereby eliminating a middle step.

(3) Public guardian and trustee to be available and accessible at all times.

(4) Decision-making by public trustee to proceed without delay; eliminate case managers; staff office of PGT with health care providers to provide necessary support.

We thank you for your attention and we'd be happy to answer any questions.

**Mrs Johns:** The Consent and Capacity Board—I was interested in your philosophy of not having a board. We put that board there to have a quick, cost-effective ability for people to appeal decisions they didn't like. To go to a judicial body, as you suggest, I believe would be costly and time-consuming. I'd like you to comment on that.

My second question is about rights advice. As a doctor, as a health practitioner, I'd like to know what you believe is your obligation with respect to telling people they're incapable and what rights you believe you should be giving them if they don't seem to agree with your decision.

**Dr Riddle:** Under the current situation with the rights advice—I'll answer that one first—there is a whole document you're supposed to read to a patient which is incomprehensible to anybody who's incapacitated, and I don't know as it's comprehensible to the health care provider either, in most cases. But I do think the patient should be informed: "No, I don't think you're understanding what I'm telling you. I would like to be able to talk to somebody who can assist you in this so you can help understand it and we can have a better way of understanding what you need and what we believe would help you out." They certainly need to be informed that there's something needed, but I don't think you need to go into a long document that doesn't assist in understanding anything.

As to your other question, there's been some experience with the Consent and Capacity Review Board where they have been asked to intervene, and when doing so, they end up at the end of their discussions saying to the incapacitated person, "Do you accept this substitute decision-maker on your behalf?" and the person who is maybe paranoid or worried about what information they're going to receive says, "No, I don't want to have them." They've not gained anything. There is no one who's going to then take their role and help them make the decisions. They've come full circle and accomplished

nothing. If that's what the board is going to do without actually making a decision, it's a waste of time.

**Ms Katz:** The experience we have seen with administrative tribunals or quasi-judicial tribunals is that in theory they make a lot of sense—it is easier to go before a board of this kind than it is to go before a formal proceeding in a court—but what happens is that an appeal is almost always launched to a court and in essence you're delaying the final decision-making process. In fact, you're incurring greater expense both for the system and for the litigants, the people involved. They're going to hire their lawyers; their lawyers are still going to appear before the boards. The boards have become formalistic, only now you don't have the rules of evidence to protect the interests of the needy. We look at the Workers' Compensation Board, we look at the Human Rights Commission; they're all boards and there are some real concerns with the decisions rendered and a lot ends up in court anyway. So I don't see that the theory actually plays out in practice.

**Mr Richard Patten (Ottawa Centre):** Thank you for your presentation. I gather your report talks about flexibility, less red tape, addressing some the cost issues. As to your idea of having a roster of public guardians and trustees who would be available, how would you see this being managed on a practical basis in an area?

**Dr Riddle:** There should be a central number or a regional number that you'd phone. Somebody could be contacted by pager almost within minutes so that something gets done right away, rather than waiting until the weekend is over, if you're on a holiday weekend, a long weekend. Somebody is in need of treatment; they're not life-threatening, they're not in an emergency, but they're uncomfortable and their situation might deteriorate if they don't get expeditious treatment. To have somebody there who's trained, able, equipped and ready to make a decision on behalf of the incapacitated person is what's needed.

**Mr Patten:** So a central registry to which institutions could plug into and there'd be one call. I'm moving quickly because there's another area you talked about, and I've experienced this and have had calls on this; that is, the abusive people who may even be guardians or named on behalf of an incapacitated patient, especially in terms of financial abuse. I wonder if you'd elaborate on that, because that's a mechanism that isn't really addressed here.

**Dr Riddle:** I work in three nursing homes and visit three others on an interim basis. In any of those you can find over time that there are people who have had their assets converted by a family member who is supposed to be their substitute decision-maker. Everything's sold, invested, whatever, and there's nothing left to pay the debts. They walk away; the parent dies and a \$6,000 bill is outstanding and there's nobody around to collect from or take responsibility.

We've even had a case where a son believes his father's going to live to 120. He's 88, and he's been using curtains as toilet paper—just to show evidence of his status—and he's yelling at him to get up and get walking, get exercising and so on. Who do we call on

who's going to come in and help protect this gentleman? We see the abuse, but we don't have a lot of authority. We try and run interference, but every time this guy was in a different institution, he had his lawyer on their backs because he was going to threaten this institution or that institution. There's abuse out there, and we need some form to help protect against that kind of abuse.

**Mrs Boyd:** I have to admit that I'm quite puzzled by your presentation in a lot of ways. If I look at the four recommendations, it would be hard to disagree with (1) or (3). In fact, I think (3) is the case; there are regionalized offices. I don't know whether the current government has cut back on the funding, but we had already set up some regionalized offices and an arrangement for people to be available 24 hours a day. If that's not happening, it was certainly always intended that the PGT would be available. I'd like some research done, actually, into the statistics that the PGT has had around calls and what exactly has happened there, because that's a very important issue and I think we should see it.

But the thing that puzzles me is that you talked just a moment ago about the need for someone to intervene in these cases, and that's exactly what the Advocacy Act did. It provided for people the opportunity to intervene when there was a situation. You would have someone to call—the advocate's office—who would then be able to do the investigation and protect your patient, yet you say you applaud the repeal of the act. I have a problem with that.

I think most of us think of our family physicians as being among our greatest advocates. Most of us believe that. Yet what consumers have said coming in front of this committee and in front of every other consultation has not been just suspicion of health care providers—very seldom their family physician; mostly other health care providers—but that these are the things they need. Yet as we go through here, all the things that consumers say they need most, you folks seem to be saying that you want this government to remove. That worries me, when I think of my family physician as one of my greatest advocates and one of the people I could count on to represent the vulnerable most effectively. I'm not sure what's going on, and I don't quite know how to respond to you.

**Dr Riddle:** We believe we are patient advocates. That's one of the things we're trained for and one of the things we endorse and want to carry out. The tone of the current legislation is that health care providers are to be feared. The tone seems to be, "Hey, these guys are something to watch out for, what they might do to you." I don't like to think we fit that role at all.

**Mrs Boyd:** I would say most of you don't. In fact, family physicians were among the people who came to us most desperate for solutions to the problems for their patients, whether they were facing abuse in institutions, whether they were facing abuse from their families or from their guardians, whether they were facing neglect because they had nobody. Those were all problems that were brought to us by family physicians. All the work that was put together in terms of the Advocacy Act, in terms of having substitute decisions available, getting

case management of the PGT, all those things were in response to those kinds of problems brought forward by family physicians.

**Dr Riddle:** I personally haven't had a lot to do with it, other than one case where an advocate was speaking to a crowd of which I was a member. This fellow was reiterating how he was so badly abused in his youth, and he very clearly had an axe to grind and he was going to get back at those health care people for doing what they did to him. That's what makes people very apprehensive in the health care field, that if they're out to get us, we're not really going to be working effectively as a team. There's always going to be some apprehension, and that's not going to be very effective care.

**The Chair:** Thank you, doctors. The time is up. I appreciate your presentation.

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## PSYCHIATRIC SURVIVORS OF OTTAWA

**The Chair:** Psychiatric Survivors of Ottawa, Mark Parsons, the advocacy coordinator. Welcome.

**Mr Mark Parsons:** Hi. How's everybody doing? Are you hanging in there?

**The Chair:** We're doing very well. You have the floor and may proceed at your convenience.

**Mr Parsons:** Thank you very much. My name is Mark Parsons. I work with the Psychiatric Survivors of Ottawa. I have a brief. Do I hand them out, or do you just want to listen to my wonderful voice and not read? That's an option; sometimes that's more helpful.

I work with the Psychiatric Survivors of Ottawa, a self-help, peer-support group that focuses on building voluntary, informal supports and advocating for changes in systems that affect the lives of individuals who have had and continue to have mental health problems.

I'm not an expert but a representative of the collective experiences of our membership. That is what I hope to bring to you today. All irrationalities and inconsistencies of thought are my own, and I hope there are at least some in here.

I plan to be short and to stick to my script.

Our immediate comment is that the changes proposed in Bill 19 peel back an enormous amount of discussion and debate in a very short period. The process the government has chosen to implement this plan seems to us inadequate to the task it sets itself. In the rush to divest ourselves of the Advocacy Commission, we are not looking adequately into the future of the services and the systems that are now being utilized. When looking at this legislation, we asked ourselves, does Bill 19 help implement the mental health reform processes that Ontario's last three governments have supported?

The issues we hope to touch on here are the role of rights advice in mental health—what should it look like?—and the role of vulnerable individuals as valid partners in the mental health system and their collective ability to participate in changes.

Other concerns, that I will not touch in this presentation but that we consider important, include the pruning of liabilities, for little particular overall gain, and the ambiguous use of language describing treatment.



The future goal of a reformed mental health system is to move resources from a treatment-focused approach with a few supports to a support-focused approach that is aided by treatment. Other jurisdictions where this has been attempted have reported developing a more efficient, focused and responsive system.

In brief, modern treatment, especially in psychiatry, attempts to take control over some of the basic neurobiological functioning in the hope of modifying distressing behaviours. Things need to be modified and changed.

Supports, on the other hand, rely on an individual's basic instincts for survival and adaption to live in their community, helping them to learn or to live through their sometimes poor choices. Nobody else will live their lives for them.

A key to allow future transitions from the community to the institutions and back to the community is a system that will be accessible, consistent, competent and understandable for the individual. Otherwise, the traditional solitudes of hospital and community will leave the system clogged and in self-competition.

Our system can at times choose not to serve our most needy and vulnerable citizens by focusing almost exclusively on the power of treatment within four walls instead of community supports. Treatment often consists of the ability to detain individuals for their own—and sometimes the community's—best interests, and the ability to dispense medications.

I had a discussion with a psychiatrist working in a provincial hospital once, known to be too honest for his own good, who informed me that he spent the largest part of his time acting as a policeman and most of the rest of it writing prescriptions. He seemed to me to be describing his role as being reduced from a figure of authority exercising best practices to a figure of power exercising his basic responsibilities.

Our current bill emphasizes treatment, the powers of treatment, the ambiguities of treatment and the minimized liabilities of treatment.

Expertise tells us that doctors-health practitioners are figures of authority, attempting, with the aid of expensive educations, to deliver best practices to an individual in their care. Experience tells us that doctors are often figures of power, obligated to fulfil the responsibilities of their powers.

If power is truly a substantive issue, we believe there is a need to balance that power with the power of clear knowledge allowing the individual to make an informed choice about the totality of proposed and possibly imposed treatments. Rights advice is still a necessary component of the Mental Health Act, and clarity, accessibility and consistency is still a necessary component of rights advice.

What is the goal of rights advice?

A friend of mine, wise in the ways of hospitalizations, not too long ago felt the need to challenge a psychiatrist's decision to keep him in an institution. The psychiatrist felt that treatment was necessary and that he needed to exercise his responsibilities and detain my friend in order to effect said treatment.

My friend, on the other hand, saw himself as a social being, not as a biological entity, having to meet the needs

of an individual in the community. He was staying at the time in a city different from the city he had been hospitalized in, and he needed to effect changes to his living situation in order to have a place to call his own. Without fulfilling those needs, things would go badly for him, no matter how well the treatment went.

Expertise tells us to treat those in our care to overcome poor behaviours and bad choices. Experience tells us that we function in the community, at least 95% of the time anyway, and personal needs expressed in order to fulfil that role are at least equally important.

With a clear understanding of his right to challenge the treatment-detainment decision, he took it to review board and it decided in his favour. Apparently, expertise can be modified by experiences and the expression of needs. His knowledge of the review system helped him act upon his view of himself as a citizen with responsibilities, not merely as something to be corrected or managed. It is the accessibility and understandability of one's rights that allows individuals to project themselves as something more than a burden on the treatment system.

Overreliance upon treatment and little reliance on linking treatment to the greater whole we believe significantly reduces the ability of our mental health system to reorient itself towards supports. Four-walls treatments do not necessarily meet the needs of those most vulnerable and their community.

A member of ours, with a number of deeply felt anxieties and insecurities due to past experiences, could not bring himself to use the treatment-based health system. He relied on informal community supports like our own, his neighbours, his landlord, his mother etc, people who had little or no power over him. We could not arrange for more formal, ongoing community supports. There was no current availability, and because of the immediacy of his feelings it was difficult for him to get in line for them.

Unfortunately, his fears got the better of him one day and he decided to leave our fair city and travel. He stopped in another North American city, and without his informal support network, he was quickly institutionalized. No treatment they offered him worked. He knew this would happen because he had been treatment-resistant in the past. His increasing despair and fear caught up with him. He managed to run away and on a beach in yet another North American city his life ended.

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We believe, because the formal system offered him unwanted treatment and powerlessness and little else for his fears, his life ended more tragically than it should have. Our mental health system made it very difficult for him to make the choice of a mostly supports system instead of a mostly treatment option. The combination of volunteer organizations and conscripted volunteers of family and neighbours were inadequate in and of themselves to help him live through his sometimes poor choices.

Expertise tells us about history, best practices and responsibilities. Experience tells us about the here and now, individuals and the need to live their lives.

The need for vulnerable individuals to come together and provoke changes in the way resources are used to

meet their needs and the community's needs are critical in creating, not a perfect system with a volunteer Poly-filla, but a system of process, change, responsiveness, individuality and continued trial and error.

Our deepest concern with the current legislation is that it projects the four-walls treatment mentality despite the fact that, in use, it is a small part of the whole. It provides little in the way of linkages or acknowledgement of present and future community supports.

Traditional liberal societies like our own, because of a belief in imperfect human nature, have generally sought to balance all powers that it can recognize.

We believe we need to balance the powers of detention, treatment, authority and expertise with the powers of rights, accessible knowledge, and the power to instigate changes on a community level when experience seems to dictate.

**Mr Patten:** Thank you, Mr Parsons. I can see that this means a great deal to you, and I thank you for coming today. When you talk about the balance, successive governments have talked about the process of deinstitutionalizing over time, as you well know, and providing more community supports. Some of the deinstitutionalization has taken place without the community supports being in place, and you address this somewhat in your paper. I have two questions for you, quickly because I only have two minutes. Could you be more specific on the nature of some of those supports? And what impact does having Brockville so far away from the Ottawa community have in terms of the community you're trying to represent at the moment?

**Mr Parsons:** Brockville—what an issue. But to answer your first question, the kind of community supports we are looking at have been defined by mental health reform. There are many documents speaking on it.

It considers four priorities: case management; the ability to—I hate the word—support people where they live in a manner they choose to be supported; housing supports, finding the ability to choose housing in their community and keep that housing; peer and family supports, supporting their peers and building family supports. Can somebody please inform me of the fourth one? I can't remember now. I'm sorry.

These are the traditional answers to moving resources away from institutional to community-based resources. They help people live in the community, they recognize the need for people to be there and they do their best to meet their needs there.

The issue of Brockville: Brockville stands a good couple of hours away from Ottawa. All our long-term-care needs are supposed to be met by Brockville. In the short term, Ottawa meets needs, but in the long term, any needs of somebody who has extended health care needs, like psychogeriatric people, older people with psychiatric problems, or people who need long-term care on occasion are delivered from Brockville. They are very far from the community of choice, and we've had many, many discussions with the ministry about how to bring some of those resources to our community. It's been a very long discussion, and not a very fruitful one.

**Mrs Boyd:** Thank you very much for coming, Mr Parsons, and for sharing with us the views of yourself

and I gather your self-help, your support group, because it is important for us to know. I'm curious as to whether you saw as one of the supports that would be available to you the existence of the Advocacy Commission, having advocates within the community, or whether in fact you have another vision of how to achieve that kind of advocacy support within the community.

**Mr Parsons:** We did support the Advocacy Commission's creation. It was an important option, we felt, to develop a consistent and open rights advice system and to develop ways in which to build the community so it could advocate for itself for changes and see that as a community process rather than a confrontational process. We felt that that would be a really good goal of the commission and that it was possible. I realize that the present government finds it as being something else, but we felt that it was a good response to meeting the needs of vulnerable individuals.

**Mrs Boyd:** So you are fearful, as we are, that the repeal of the act will leave yet another gap in what I gather from your presentation are many gaps now for people within your community who are survivors.

**Mr Parsons:** It leaves the gaps that were always there. The Advocacy Commission came in less than a year ago. We felt that it was the opportunity to build a support-based system, that that was a real goal of mental health reform and that it was there to ensure that was to happen. We reverted seemingly back to treatment-focused and looking back rather than looking to the future about what we want for the people who live in our community. The goal of advocacy was to develop a different role for our community and a different role for people to play by using both volunteers and paid rights advisers.

**Mrs Boyd:** And self-advocates, of course.

**Mr Parsons:** And of course self-advocacy was the key development initiative, yes.

**Mr Parker:** Thank you for an excellent presentation. You spoke very articulately and it's clear that you have put a lot of thought into your presentation and into these issues generally. I wonder if you could help us with one issue that we have been struggling with so far over the last week and a half.

Right now, in the present draft of the bill, there is no requirement that a doctor who determines that someone is mentally incapable actually advise him that he's been so found. That is not an obligation in the present draft. Some people have made the suggestion that that should be an obligation and it should be included in the terms of the statute. Others have suggested that that's improper, and there's been some discussion as to just how that news should be delivered, if it is to be included in the statute, just how directly the person should be told. The caution has been given to us that in some cases that might be harmful to the individual to be told that. The bad news would itself be a bit of a shock and it would be destructive to that individual. We've been told to tread lightly here and be careful how we proceed. I wonder if you have any advice on that whole subject.

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**Mr Parsons:** Well, being institutionalized is bad news enough. It's not going to be any less bad news to know you've been institutionalized formally. I mean, somebody



has to tell them somewhere along the line that they have been detained formally, they cannot leave, and if they think that that's not correct that they have the right to challenge or to ask for an independent review of their detention in a facility. I don't see that as necessarily harmful, any more than the institutionalization itself. I think in the long run people appreciate being given the opportunity to know that, even though at the time they may not have found that all that helpful. I think people can respect what they've been told, if not in the present then at least in the future.

Knowing that a system is accessible and open allows people to use that system more fruitfully. Running away or being frightened of the system is one of the problems of the current system, and knowing that rights advice will be available when being detained by that system is a key element in taking away fear. You know, you do have the right to objective viewing of your situation, and I think that should be built into the legislation. I don't see why it shouldn't—people should be given access to the knowledge that this has happened and what they can do about it.

**The Chair:** Thank you, Mr Parsons, for your thoughtful submission.

**Mr Parsons:** Thank you for allowing us to present. I'll thank my members for their input in this presentation and give them your thanks.

#### CITIZENS COMMISSION ON HUMAN RIGHTS

**The Chair:** Our next submission is slightly out of order. It will be Cathie Mann, the Citizens Commission on Human Rights. Welcome, Ms Mann. You're here early, so you must be eager. That's great.

**Ms Cathie Mann:** Less time to sweat and worry. It's like being called to the principal's office here. I don't know what you're going to throw at me after, you know? You know what I'm going to say.

My name is Cathie Mann. I am the director of the Ottawa chapter of the Citizens Commission on Human Rights, otherwise known as CCHR. I do this as a volunteer, and I appreciate having an opportunity to address you today.

I will start by briefing you a little bit on what my group does so you understand where I am coming from. I have been working with this group for 10 years now. In these years, I have met with, corresponded with and documented many cases of psychiatric abuse. So I have something to say about this particular group of vulnerable people.

I'm just going to diverge a little bit. I don't claim to be a legal expert and have all the solutions, but I do know what has happened in the past.

I realize there are many categories of vulnerable people, such as the elderly, those afflicted with AIDS, those who are sensory deprived and so on, but mental health is the area that I am most familiar with from the point of view of having listened to those that the system has failed. I want to tell you about some of the people I have heard from and worked with and some of the difficulties we have run into and why it is so important to have advocacy.

A young girl, 17 years old, went into the military about 15 years ago. She was sexually harassed and complained to her superiors. Nothing was done. She continued to complain. She was based in Winnipeg at the time. They flew her to Ottawa and put her in the National Defence Medical Centre. She was told it was for the estimate of damages both physical and emotional. It was also supposed to be for rest and to make a report of damages and an estimate of damages so that justice could be brought.

This did not happen. It was an assessment instead whereby psychiatric drugs were used before any assessment was even started. In fact, she was put straight on the psychiatric ward and put on drugs against her will and knowledge, having never even taken street drugs in her life before. She did not in fact even know the extent of the drugs she had taken until years later when she gained access to her medical files.

She was then flown back to Winnipeg and given a dishonourable discharge. She no longer has her trade as an aircraft mechanic and private pilot that she worked so hard to obtain while in the military. She is now on welfare and seeking justice.

Perhaps some rights advice and/or intervention, which she tried very hard to get during this time period, would have prevented this waste and saved the province some money. She knew she had rights, because she knew what happened wasn't right and was never given access or knowledge of a review board. It was bad enough that she had been sexually harassed, but then to be given psychiatric drugs and a label in answer to that was just more abuse.

Another example: A young girl, also approximately 17 years old, abused by her parents at home. Her mother used to drag her across the kitchen floor by her hair. What she needed was a good home, some love and understanding. In her case, she would probably have been better off with the help of the children's aid society.

She was put in a psychiatric hospital, given such strong medication that she could barely get out of bed, and when she did she sometimes had to hold on to the walls so she would not fall down. I also forgot to mention in here that she'd also tried to kill herself. She also received shock treatment against her will, suffers from memory loss and is unable to work.

I know these stories sound unbelievable. Until I actually started talking to people 10 years ago who had had psychiatric treatment, I didn't believe it either. What seems to have happened is that our society has become more and more dependent upon drugs, upon quick fixes. Compassion and human kindness is what we need. Actually, this is something I saw in the Advocacy Commission that was set up. Because these commissioners, each in their own way, had been there, they cared and tried to do something about the situation.

I have noticed a very disturbing trend: The life expectancy rate for a consumer-survivor is much, much lower than for the average person. I know of at least five suicides in the past three to four years.

In one case, a man who had had a head injury as a child had been given psychiatric treatment. He did not feel this was warranted and proceeded to attempt to find



scientific evidence to the contrary. He also participated in a drug study in an Ottawa hospital. I do not know what he was like prior to this, as I only met him after he had been in the drug study. He told me how he told them to stop. He told them he did not want any more drugs and how finally after the study was over he suffered the withdrawal from the drugs. He had no one to turn to, no advocates, and certainly in this case it would not have been a good idea to empower the nursing staff as advocates, as this would be a conflict of interest. Anyway, he had been in and out of psychiatric hospitals quite a lot, from what he has told me. He was terrified of being picked up and being put in a psychiatric hospital.

The last time I spoke to him, over a year ago, he called me from a hospital in Baltimore. He told me he was there against his will, and he sounded awful. He asked me to call his mother, which I did. It is thought that he went to the Baltimore area to see Dr Breggin, who is the author of several books, one of them called *Toxic Psychiatry*. Breggin is well respected in the consumer-survivor movement because he believes that people need love and understanding, not drugs and shock treatment.

Well, that was the last I heard from him. I got a call from his mother. He was dead. I called the police investigator in Georgia who was handling the case. They had figured out that he had taken the Amtrak down there, taken a bus, taken a taxi out to Jekyll Island, walked into the ocean and never came back. Had his rights been listened to and acted on, perhaps this tragedy would not have happened. I think he had finally had enough.

As you may recall, around 1994 the Ministry of Health put together the implementation planning guidelines for mental health reform. It is my understanding that the breakdown for funding for mental health at that time was 80% went to the hospitals and 20% went to the communities, keeping in mind that the percentages, I am told, were more like 60-40 in the Ottawa-Carleton area. What was going to happen over a 10-year period was that these percentages would reverse and there would be alternatives set up in the community, thereby putting people first.

The reason I am mentioning this is because I think that some sort of advocacy would be more and more needed and indeed help the ministry's vision become a reality. After all, why do we have a government? The purpose of a government is to bring order. You want to bring order so that people can live their lives, go to work, go home, raise their families etc. We need to have a vehicle that will help facilitate this shift and help people navigate their way around the red tape.

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I will give you a short example of what I have seen happen to a few people. After having had forced treatment and having decided to do something about it a few years later, when feeling more able to handle it, they went to the police to lay a complaint. The complaint was refused and they were referred to the College of Physicians and Surgeons. A complaint was laid with the college but not really followed up on except for a few brief letters saying it was being investigated. The person then tried to file a civil suit, had difficulty finding a lawyer versed in mental health law and so on.

We need rights advice. We need a non-profit charitable corporation where at least some of the directors have disabilities. We need to strengthen the disability community. I think we have a responsibility to care about what happens to our fellow man. I think that in this way you can save and not waste money, because some of these disabilities that have been created could have been prevented in the first place. You don't have to believe me. Just look at the number of complaints the College of Physicians and Surgeons of Ontario receives every year. Thank you.

**Mr Marchese:** I just want to say that the case examples you give are very, very important, because we tend to lose sight of what we're really trying to do here at times. It's only by hearing these case histories that we realize what we're trying to do. We take the axiom of one individual who stated it as follows: Society's judged on how it supports its least able. If we can't support our least able in a way that protects them, then we as a society are not to be looked upon very, very favourably.

The problem is that we tend to forget that the reason why we put in place, the previous government at least, the commission and the rights advisers was to deal with these kinds of situations. Overall it may not solve all of them—obviously one is aware of that—but you need something in place. I agree with you when you say that governments are needed. This government says we need to get the state out of your hair, but if we do that, then who protects the people you spoke about? Would it be volunteers? Would it be the families? Would it be some other agency that has been out there in the past to do this work? Are they there?

This government says, "We might have something in place." I'm not sure. They talk about having something in place. I don't believe it, to be frank. But I'm worried about that. Are you worried about what would happen to people like the ones you described if we leave it to a system of having volunteers look after this or just families look after this, assuming that all families are good and assuming everybody has a family?

**Ms Mann:** I really wouldn't it want to be just volunteers. I really appreciate what you said. I was trying to give examples. These are very real case scenarios. Actually, I could go on for pages on things that have happened.

**Mr Marchese:** I'm sure you could.

**Ms Mann:** What I really see is some kind of a liaison where some of the community groups have some kind of access to maybe an official outside board of some kind when a person does go to complain—obviously, when you're in a hospital you're at your most vulnerable—where they have someone they can go to who can do something and has an authority to say, "Listen, this person hasn't had their rights complied with." When you're a volunteer, you're a volunteer. You're not recognized; you're a volunteer. So it does have to be somebody.

I do have faith. I'm not a political-type person. I tend to believe in whoever is honestly trying to do the best thing that's going to do the most amount of good and the least amount of harm. I think the Advocacy Commission was forging ahead, but that's not to say that another



government can't come up with something as good or better. I'm not an expert in the area.

**Mr Clement:** The last comment should be a challenge to all of us to come up with something that is better and that works, and I thank you for that last comment.

One would not have a pulse if one was not affected by some of the stories that you have just shared with us. As politicians, the tendency is to then say: "Something must be done. I don't care what it is, but let's do something, anything." Please forgive me when I say we have to resist that to the extent that we have to do what actually will work. Sometimes governments do things because they just want to do something, and the law of unintended consequences means that tragedies are multiplied rather than solved.

I'm very interested in your second-last paragraph where you talk about the non-profit charitable corporation, which of course Mr Reville has been talking about. I guess I have two questions and I'll say them both at once. What's stopping you now from doing a non-profit charitable corporation? If the answer is money and provincial involvement, my second question would be, wouldn't it better to have a truly independent non-profit corporation that need not rely on government and need not be in any way directed by government?

**Ms Mann:** There are many non-profit charitable organizations actually operating throughout the province and throughout North America that have been trying to address this area. Most of them are support groups. But when you're a non-profit charitable organization, you're not a government official. If you go to the police and try to get some rights wronged, they'll send you elsewhere. I know this from experience.

If you don't mind, I want to just take this opportunity to tell you what I was really hoping for and what I was looking at. I was really happy a few years back when this mental health plan came out, because what I saw—this does fit with this, right? If this were to happen, then there would probably be more consultations in the community. There would probably be some things set up in the community. I'm sure some people would be willing to volunteer their services and to tell what's needed.

The biggest problem of people coming out of a psychiatric hospital is getting off the drugs—the biggest problem. Where do they go to? An ordinary physician is not prepared to handle that. There are a lot of things that need to be put in place, and I see advocacy as a beginning.

**Mr Patten:** Thank you, Cathie. I'd like to pursue a little bit as well. You make reference to one model that works with younger individuals, the children's aid society and the responsibilities they have when someone feels that something should be investigated and they immediately have a particular source. I would like to pursue the thought. Are there organizations that would not need to be set up totally but might be able to adopt that kind of a function, by reference, with the addition of some skill that may be in the legal area, at least a good understanding of the legal area and certainly a knowledge of the rights of individuals, but can build off of its strength and knowledge in the whole area of mental health?

**Ms Mann:** I think that's an excellent idea. A lawyer would be in the position where he could say and do something. I know that there are some lawyers who actually do have a problem. You have a hard time finding a lawyer who even understands how to fit the Mental Health Act with the rest of the laws, because a lot of the things that go on are things that would be considered to be assault in the ordinary laws but they're not an assault. Sorry, I don't know all the legalese on this, but when you take it and you look at it, somebody who's been forcibly drugged, that's an assault. I know that there are certain lawyers in town, one in particular, and he for a number of years has been working with people who have been in the psychiatric institutions. If he, for example, were empowered with that, that would help him a lot, because right now legal aid does not want to fund him fighting the psychiatric system.

**The Chair:** Thank you very much, Ms Mann. That completes your time.

1700

#### INTERVENTION DES SOURDS FRANCOPHONES ONTARIENS

**The Chair:** Mr Laurent Deguire will be presenting the last submission of the day. He is francophone and deaf. Ms Translator, could you give your name into the microphone so that we have that on the record.

**Ms Monique Deguire:** I am Monique Deguire.

**The Chair:** Thank you. You can proceed and translate to us what Mr Deguire would like to say to us.

**M. Laurent Deguire (Interprétation) :** Ça me fait plaisir de présenter mes idées. Je vais faire mes signes lentement, parce que mon interprète n'est pas professionnelle. Il n'y en avait pas de disponible aujourd'hui, malheureusement. Je pense que tout le monde peut comprendre qu'on va aller lentement. C'est important que tout le monde comprenne ce que j'essaie de dire en signes. Si l'interprétation manque trop, il va y avoir une mauvaise communication et puis ça va défaire le but.

J'ai six sujets à adresser. Premièrement, avant les six sujets, mettons un peu de contexte. Moi, je suis une personne sourde, pareil comme tous les autres personnes sourdes. Ça n'existe pas pour moi, une langue française, ni l'anglais. Ma langue principale, ma langue maternelle, c'est les signes et c'est différent d'une langue entendante que vous parlez. Les sourds ont un langage complètement différent. Votre langue des entendants, c'est ma seconde langue. Ma langue maternelle, c'est les signes et ma langue parlée, c'est ma deuxième langue.

La culture sourde communique avec des expressions corporelles et des signes, en images, en idées. Les signes, c'est une langue profonde en elle-même. N'oubliez pas qu'un sourd n'est pas capable de communiquer facilement avec un entendant, ni de prendre simplement un texte et de le lire. La lecture, tous les sourds sont faibles, ils ne sont pas capables de comprendre ce que ça veut dire, la structure de phrases entendantes. C'est complètement différent.

Maintenant, je retourne à mes sujets que je vais adresser, premièrement sur l'éducation. Il y a beaucoup de sourds qui rêvent de participer aux études à différents

niveaux, étudier pour avoir la chance d'obtenir un bon travail comme vous-mêmes. Mais il y a un manque de services d'interprète à cause des manques de fonds. Mais le gouvernement provincial de l'Ontario transfère certains fonds à toutes les écoles, à tous les niveaux d'école pour supporter les besoins spéciaux, les étudiants avec des besoins spéciaux. Mais malheureusement, c'est trop cher pour les interprètes, c'est trop cher pour les tuteurs parce que les administrations personnelles des écoles qui sont autonomes coupent continuellement leurs budgets et disent aux personnes avec les besoins spéciaux, «Je regrette.» Moi, je suis bloqué puis je n'ai pas de futur.

Maintenant, les compagnies obligent tout le monde à avoir des diplômes. Moi, je n'en ai pas ; les personnes sourdes n'en ont pas. Alors, comment on peut entrer ? On est faible ; on est vulnérable. La langue est faible pour communiquer. Il y a souvent des personnes qui vont suivre la formation pour devenir interprète et qui réussissent le programme mais qui ne sont pas compétentes. Alors nous, les sourds, on perd notre but, nos rêves d'avoir un bon futur comme une personne qui est moins vulnérable, qui est entendante.

Une des preuves, il y a un article qui était passé au Citizen qu'un homme sourd essayait de suivre des cours au Collège Algonquin, et puis il n'était pas capable d'avoir des interprètes. C'est ça. Ils ont été coupés parce qu'il n'y avait pas d'argent et il n'y avait pas d'interprètes compétents.

La Commission des droits de la personne a de la difficulté à intervenir parce qu'à la Commission on ne connaît pas la culture et les problèmes, et le système qui est nécessaire pour les personnes sourdes. La Commission devrait avoir les compétences pour le système des sourds, comment ça fonctionne, la communauté sourde, mais ça n'existe pas. Vous, le gouvernement de l'Ontario, avez créé la Loi 4, le projet de loi 168 et aussi 114, je crois, au sujet de l'éducation, qui couvre aussi les sourds et l'interprétation en LSQ et ASL pour les sourds à l'école. On l'a créée, et partiellement c'est correct, mais pour le reste, non ; ça ne fonctionne pas.

**1710**

Les sourds sont frustrés. Ils savent qu'ils ont une loi pour les supporter. Ça, c'est aux niveaux primaire et secondaire. Ils ont des droits dans la loi pour supporter qu'il y ait accès à l'éducation dans leur langue, mais ce n'est pas toujours l'expérience à cause de l'argent. Les écoles refusent les droits.

Deuxième sujet : le système judiciaire, c'est grave. Souvent, la police arrête une personne sourde. Quand la police arrête une personne sourde et ne connaît pas les signes, ne sait pas communiquer avec la personne sourde, ce n'est pas des vrais signes ; c'est comme des mimes. Ce n'est pas la vraie langue des signes. Le sourd ne comprend pas et la police le met en prison. Des fois il doit attendre trois jours pour avoir un interprète sans savoir ce qui se passe parce que le sourd ne sait pas qu'est-ce qui se passe. Il doit attendre pour avoir un interprète trois jours dans la prison. Ce n'est pas normal.

Souvent, la police ne respecte pas la loi sur les handicapés, qu'il faut avoir un interprète pour une personne sourde. C'est important de savoir pourquoi on se fait

arrêter. On n'a pas de raison. On ne comprend pas. C'est souvent. C'est un rapport qui a été fait par OAD.

The Ontario Association for the Deaf did a report and had some fact situations it was reporting. The one that Laurent was referring to is a deaf man who had been arrested and escorted by the police during a stat holiday. He had to stay in jail for three days until an interpreter arrived to interpret with him and the police to make the statement. The group questions why he had to stay in jail for three days for a very small reason.

Il y a plusieurs exemples, mais juste un résumé pour montrer qu'est-ce que ça veut dire.

Troisième sujet : service médical, les hôpitaux. Tout le monde qui est sourd a peur. Les sourds n'ont pas confiance aux médecins. Souvent, à cause des différentes langues, la communication est difficile et il arrive que le médecin donne une mauvaise prescription parce qu'il n'a pas compris ce que le patient, la personne sourde, essayait de dire. Le médecin n'a pas compris ce que la personne sourde essayait d'expliquer en tant que symptômes, de problèmes de santé.

Les sourds demandent souvent, «S'il vous plaît, un interprète.» Le docteur refuse. Le docteur dit, pour obliger, que je peux écrire. Mais le docteur lui-même est savant. Il utilise des mots qu'un sourd ne peut jamais comprendre. Ça ne marche pas, lire un texte écrit, et moi comme patient, je ne suis pas capable de m'exprimer pour que le médecin comprenne. Il n'est pas capable de me comprendre.

Aussi, souvent le docteur pense qu'un sourd peut être un malade mental et l'envoie à l'hôpital pour ceux qui sont handicapés mentalement. Un sourd n'a pas de problème de santé mentale. Un sourd n'est pas stupide. Un sourd est intelligent et visuel et il est capable de communiquer profondément en signes. On est capable de vivre, comme moi avec ma femme ; on a des enfants, nous avons une ferme. Moi-même, j'ai étudié en droit. On n'a pas de problèmes mentaux, mais souvent ça arrive qu'un médecin veut référer une personne sourde.

Les sourds des États-Unis et du Canada ont des liens forts entre les deux pays. Un patient sourd à l'hôpital, Jean-Marie Paré, une personne sourde lui-même, faisait une dépression. Il a perdu son travail et il a paniqué. Ils l'ont envoyé à l'hôpital Royal depuis 1984 jusqu'à aujourd'hui. Ce n'est pas normal. Il vivait. Il était découragé, il avait perdu son travail, puis ils l'ont enfermé à l'hôpital.

C'est un conflit avec les droits de la personne. Les sourds gardent des liens et observent beaucoup ce qui se passe aux États-Unis, parce que la population sourde est beaucoup plus forte et avancée. Ils ont peur aussi. Il y a eu un article, je pense encore dans le Citizen, où ils ont trouvé un homme de race noire qui était dans une institution mentale pendant 69 ans parce que l'homme est sourd et ils n'ont pas pu évaluer le problème ; ils l'ont juste mis en institution, puis finalement il est sorti après 69 ans. Ils ont découvert qu'il était simplement sourd. C'était le seul problème.

La population sourde étant visuelle, ça marque. Ça marque beaucoup quand ils voient quelque chose et ils deviennent craintifs, beaucoup. C'est déjà arrivé au Canada, ici aussi, à quelqu'un depuis 1984, et il est encore là aujourd'hui.



Aussi, c'est important de savoir qu'un sourd, ce n'est pas une machine. Ça veut dire, une personne sourde — il y a un groupe qui s'appelle Colère-Sourds ici à Ottawa et en France. Les sourds sont beaucoup contre l'implantation cochléaire et se sentent comme des cobayes utilisés pour faire des tests, comme si c'était expérimental. Beaucoup de sourds ne sont pas d'accord avec ça. Ils sont humains et ils ne veulent pas se faire utiliser comme une expérience, un test.

**The Chair:** Mr Deguire's time is technically up. I will permit five more minutes. He understands that we are flying to London tonight and must make a plane.

**M. Deguire (Interprétation) :** Je fais un résumé. Tout le monde sourd est vulnérable et très frustré. Toutes les portes sont fermées. On n'est pas capable d'avancer. Il n'y a personne pour nous guider, intervenir pour nous, de notre part, parce que les sourds ne connaissent pas le système judiciaire, ne connaissent pas leurs droits. Ils n'ont jamais appris ; ils ne savent pas comment se défendre. C'est très grave comme on est ignorant sur le sujet. C'est très rare, quelqu'un comme moi qui peut un peu guider en droit ou sur le sujet. Je suis capable de lire de base. La population sourde était très frustrée et déçue qu'ils avaient fermé la Commission d'intervention, parce qu'ils ne savent plus où aller pour avoir du support de la direction. La Commission des droits de la personne n'a pas les compétences, n'a pas le temps, ne connaît pas la population sourde. Souvent ils n'ont pas de compétences dans le domaine.

Le gouvernement a écrit le Code des droits de la personne provincial. C'est écrit là-dedans que c'est interdit, la discrimination contre un sourd, mais je subis toujours la discrimination et je suis vulnérable. Ça continue toujours. Où est ma protection ? Il n'y en est pas. C'est très vulnérable. C'est sérieux. C'est comme une crise de vie. Les entendants sont confortables. Les sourds, 360 000 sourds au Canada — je n'ai pas le

chiffre pour l'Ontario. Je ne l'ai pas encore. Je vais le recevoir bientôt.

Je vous remercie. J'espère que vous allez réfléchir parce que nous avons besoin d'un intervenant. Le gouvernement provincial a écrit dans la loi sur les droits de la personne «sans discrimination pour les handicapés». Sinon, c'est inconstitutionnel. Merci.

**The Chair:** Could you thank Mr Deguire and tell him I'm sure that the committee has more understanding of the problems and challenges facing the deaf in our province.

1720

**Mr Patten:** Can I say something for just one minute? Je veux dire félicitations. Je sais que ça prend beaucoup de temps de dire les mêmes choses, mais avec une interprétation, ça prend plus de temps. Il me semble que vous avez noté essentiellement deux grandes choses : premièrement, à cause de la mauvaise communication, quelqu'un perd ses droits, et deuxièmement, vous avez suggéré une solution, peut-être un réseau, un bureau, d'avoir 24 heures par jour un service pour les gens qui ont besoin d'un service immédiat auprès de la police ou d'un hôpital ou d'autres situations d'urgence. Peut-être pourra-t-on en discuter après la session ici. Merci pour votre présentation.

**M. Duncan :** Je veux aussi dire merci pour votre présentation. Je veux indiquer que la discrimination contre les sourds est triste et que je regrette ces problèmes, mais je pense que la loi qui existe maintenant, selon les avocats, ne s'adresse pas à la question des sourds et la discrimination, la plupart de ce que vous exprimiez aujourd'hui. J'espère que nous pourrions avoir une opportunité de parler de toutes ces questions pour les sourds dans l'avenir avec un autre comité de la législature.

**The Chair:** Thank you very much. We're adjourned until 9 o'clock tomorrow morning in London.

*The committee adjourned at 1727.*





## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

**Chair / Président:** Martiniuk, Gerry (Cambridge PC)

**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

\*Boyd, Marion (London Centre / -Centre ND)

Chiarelli, Robert (Ottawa West / -Ouest L)

Conway, Sean G. (Renfrew North / -Nord L)

\*Doyle, Ed (Wentworth East / -Est PC)

\*Guzzo, Garry J. (Ottawa-Rideau PC)

Hampton, Howard (Rainy River ND)

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\*Leadston, Gary L. (Kitchener-Wilmot PC)

\*Martiniuk, Gerry (Cambridge PC)

\*Parker, John L. (York East / -Est PC)

\*Ramsay, David (Timiskaming L)

Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Oriole L) for Mr Conway

Clement, Tony (Brampton South / -Sud PC) for Mr Tilson

Duncan, Dwight (Windsor-Walkerville L) for Mr Chiarelli

Johns, Helen (Huron PC) for Mr Hudak

Marchese, Rosario (Fort York ND) for Mr Hampton

### **Also taking part / Autres participants et participantes:**

Patten, Richard (Ottawa Centre / -Centre PC)

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** Swift, Susan, research officer, Legislative Research Service

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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Wednesday 14 February 1996

# Journal des débats (Hansard)

Mercredi 14 février 1996

## Standing committee on administration of justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

## Comité permanent de l'administration de la justice

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
Greffière : Donna Bryce



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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Wednesday 14 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Mercredi 14 février 1996

*The committee met at 0900 in the Radisson Hotel, London.*

ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

**The Chair (Mr Gerry Martiniuk):** Good morning, ladies and gentlemen. This is the second week of hearings of the standing committee on administration of justice, consideration of Bill 19, Advocacy, Consent and Substitute Decisions Statute Law Amendment Act.

**Mr David Ramsay (Timiskaming):** Where are we this morning?

**The Chair:** We're in London, Ontario, my alma mater. There are some changes I'll give you. They'll come up during the morning, but at 10:20 we have the Action League of Physically Handicapped Adults instead of Bill McCormick; at 10:40, Jennifer Wilcox instead of the named organization; at 11, the Canadian Mental Health Association of London-Middlesex and Waterloo region. That's about it.

We first have Mr Winninger, who is a solicitor and, I understand, a former MPP for this area. Welcome, Mr Winninger.

## DAVID WINNINGER

**Mr David Winninger:** Thank you to the committee for accommodating me here today. I have left a copy of my paper with the clerk and I understand she'll copy it when she gets back to Toronto.

**The Chair:** Fine. You have 20 minutes, including questions. You may proceed.

**Mr Winninger:** As a lawyer presently who frequently is called upon to draft powers of attorney for property and personal care, and as one who appears regularly before the Consent and Capacity Review Board, soon to become the Consent and Capacity Board, I continue to have an interest in this legislation.

In my former position as parliamentary assistant to the Attorney General, I was responsible for steering Bill 108, the Substitute Decisions Act, through the justice committee in 1992. Bill 108 and its companion legislation, Bill 74, Bill 109 and Bill 10, as you know, were finally proclaimed in the spring of 1995. I've published an article on the legislation in the Canadian Journal of Health Law and Policy entitled "Incapacity and Autonomy: Striking a Balance," as well as Lawyers' Weekly and other publications. I've also been asked to speak on the subject to the Canadian Institute of Law and Medicine and at other educational meetings.

In my opinion, Bill 19, introduced by the current government, combines some prudent changes to the Consent to Treatment Act and Substitute Decisions Act, with some less than prudent changes. The repeal of the Advocacy Act, however, constitutes my greatest disappointment, as you can well imagine, and I propose to deal with the repeal of the Advocacy Act first.

The health and activity limitation survey conducted in conjunction with the 1986 census revealed that over one million adults in Ontario at that time, or 16% of the population, had some type of physical or mental disability. Many of these people may be characterized as vulnerable.

In 1984, the late Father Sean O'Sullivan was asked by the Conservative government of the day to review the situation of vulnerable people and determine what protections could be put in place for them, including the physically disabled, the developmentally challenged, frail seniors and psychiatric consumer-survivors.

Father O'Sullivan, after consulting widely with lawyers, physicians, psychologists, other health care providers, consumers and a wide variety of stakeholders, published his report entitled *You've Got a Friend*. This report recommended the establishment of a province-wide system of paid, professional advocates.

Father O'Sullivan's report collected dust for a number of years under the Liberal government. Meanwhile, the tragic death occurred of Joseph Kendall, a resident of Cedar Glen, an unregulated boarding home near Orillia, due to abuse and neglect. The Ernie Lightman commission was appointed to inquire into unregulated residential accommodation in which adults vulnerable adults reside. Finally, in 1992 the NDP government passed the Advocacy Act which this government is now, with the stroke of a pen, rescinding.

The Advocacy Act was designed to assist elderly and disabled people who cannot speak on their own behalf to have a voice. Who will now safeguard the vulnerable from neglect, exploitation and abuse? Advocates provide the tools and information necessary to allow these people

to make their own informed decisions regarding medical care, personal care and financial decisions and to have those decisions respected. These necessary protections are withdrawn under Bill 19.

The Consent to Treatment Act ensures that a patient receives information about treatment, alternatives, risks, side effects and consequences of refusal of treatment through the intervention of rights advisers. Who will now explain the effects of a finding of incapacity and the right to have a finding reviewed by the Consent and Capacity Board or the courts without rights advisers and advocates? Furthermore, who will now provide the kind of systemic advocacy required to break down barriers to fair and equitable treatment and prevent serious harm to the health and safety of vulnerable adults?

I strongly urge the committee to pass an amendment that would withdraw part I repealing the Advocacy Act.

Consent to Treatment: Subsection 2(1) of the Health Care Consent Act, 1995, updates the definition of "health care practitioner" to reflect the Regulated Health Professions Act. This is desirable. However, sections 2 and 7 of the act narrow the definition of "treatment" by excluding assessments of capacity, examinations of a person's condition and treatments which pose little harm to a person. I would question whether health care professionals can always know with certainty what treatments pose little risk of harm such that they may dispose with the consent of the person.

Section 3 of the act creates the presumption of capacity for all persons. This is commendable if there is recognition of the person's wishes and preferences in treatment situations. Without advocates or rights advisers, many presumed to have capacity to consent may have difficulty making their views and preferences known. Further, I have noted that when a mental patient, for example, consents to treatment, he or she is presumed to be competent to consent. When he or she refuses treatment, she or he is more likely to be found incompetent to consent to treatment.

Section 12 of the act provides that one health practitioner can propose a plan of treatment on behalf of others involved in a plan. A health practitioner can also presume the right to make adjustments or variations in treatment or to continue treatment in a different setting if the risks and benefits are not significantly different. This makes sense to me as well. However, the bill eliminates the requirement that rights advice or a notice respecting rights advice be provided when a plan of treatment is proposed to a person found by a health care practitioner to be incapable. Many health care practitioners anxious to treat patients do not always have the time or the inclination to ensure that the rights of such patients are adequately protected.

Section 16 removes the prohibition from administering treatment during the seven-day period for commencing an appeal from the board's decision to review a finding of incapacity or the appointment of a representative for an incapable person unless one of the parties indicates an intention to appeal. Without rights advisers and advocates, a vulnerable person may not be put in touch with a lawyer or gain advice regarding the merits of an appeal.

Meanwhile, the treatment objected to will simply commence under this legislation.

Section 18 of the act no longer requires that a statement given by a person claiming to give or refuse consent on an incapable person's behalf identify his or her relationship to the incapable person, that the incapable person before becoming incapable would not have objected to him or her making a decision on that person's behalf to give or refuse consent, and that he or she believes that no person having a higher authority to consent is available, such as a guardian or attorney for personal care. Again, protections designed to ensure the authenticity of decisions made on behalf of incapable persons are being eroded.

The new act removes the prohibition on an attorney for personal care giving or refusing consent if the power of attorney was made after the health practitioner found the grantor to be incapable with respect to treatment. I am pleased that recognition is given to the fact that a person may be capable of giving a power of attorney for personal care to someone she or he knows and trusts, even if the donor of the power of attorney is incapable with respect to treatment. I think this was the case in the existing legislation, but it becomes a little more clear under Bill 19.

#### 0910

I'm also pleased that section 18 of the act clarifies that a spouse with the right to consent or refuse treatment on behalf of an incapable person does not include spouses who are living separate and apart under the Divorce Act. I suspect that the last thing an estranged spouse would want is a partner with whom he or she is no longer living making a treatment decision on his or her behalf in what could be a potentially life-threatening situation.

Further, a person may consent or refuse treatment under the new act if he or she is not present when the treatment is proposed but contacted in some other way. This is useful and practical. However, where a person purports to consent to or refuse treatment, knowing that a person of higher or equal rank exists, there should be a safeguard, such as a written statement, that the person with higher authority would not object and not merely "belief." As the section is presently worded, pursuant to subsection 27(6), health practitioners are permitted to rely on assertions made voluntarily by anyone giving or refusing treatment on an incapable person's behalf.

Paragraph 19(2)(c)1 permits the substitute decision-maker, when considering the best interests of an incapable person, to consider not only whether the treatment will improve the incapable person's condition, but also whether it will prevent further deterioration or reduce the rate of deterioration. This may in fact conflict with what are called living will provisions expressed by the incapable person while previously capable. The person deciding the best interests of an incapable person should be obliged to disclose whether he or she knows of any oral or written wishes expressed with regard to the termination of treatment where a person cannot recover from physical or mental incapacity.

I am very concerned that a substitute decision-maker can once again consent to treatment involving electric shock under this legislation and aversive conditioning on



behalf of an incapable person. I thought that was history now and I hope that the committee will consider amending that section.

Section 23 of the new legislation permits emergency treatment to be given without consent of an apparently capable person due to failure to communicate because of language barrier or disability, provided reasonable steps are taken to find a practical means of communication and there is no reason to believe the person did not want treatment. I can understand why we wouldn't want patients dying simply because English may not be their first language, and we don't want to put their lives in peril. On the other hand, it would be more reassuring if the section provided a mandatory responsibility for health practitioners to try to obtain an interpreter in these kinds of cases, both for the disabled and people who have language barriers.

I think it laudable that there will now be a scheme for obtaining consent on behalf of incapable persons for their admission to care facilities and for obtaining decisions concerning personal assistance services provided to them under personal assistance plans, but without the presence of rights advisers or advocates again, there is a danger inherent in this that the integrity of the incapable individual or even the vulnerable individual may not be fully respected.

I think it unwise, coming to the Consent and Capacity Board, that a member of the board may now sit alone—they at present have to sit in groups of three or five—and that no longer must a member of the panel dealing with an application involving capacity have expertise in evaluating capacity. This strikes me as a trifle bizarre, but that's what section 71 says. A member sitting alone on a panel is almost by definition prone to making idiosyncratic decisions, and without expertise in evaluating capacity, a great disservice may be done to the patient appearing before the board.

I also think it unfair that someone who treated or represented a patient can take part in a hearing, whether it's been over five years ago or not. The present act changes the requirement and says if you treated, or if you were a doctor, or if you were a lawyer who represented a patient over five years ago, it's okay to sit in judgement on that patient's capacity.

The hearing must be seen to be impartial. A retired psychiatrist, for example, who treated a patient more than five years ago, may have privileged information that may advertently or inadvertently affect the outcome of the hearing and, as you may know, it's retired psychiatrists who staff the current boards where a psychiatrist is required.

Finally, if the board will now only be required to furnish written reasons for its decision upon request of a patient, there should be a mandatory duty to advise patients that they may request written reasons, particularly those who may lack sufficient knowledge to request them by reason of incapacity or vulnerability.

Lastly, a word on the Substitute Decisions Act. Subsections 6(3) and 31(2) remove the responsibility of a person witnessing a power of attorney to have no reason to believe that the grantor was incapable. I believe this to be a serious flaw. It is quite possible that someone vulner-

able by reason of age or infirmity could be coerced into signing such an instrument, and I quote as my authority none other than Stephen Fram, formerly of the Attorney General's office, who may be regarded as the architect of the Substitute Decisions Act. In the Fram report he says the following:

"As with property, an attorney for personal care's authority stems only from the mental capacity of the grantor. It is therefore imperative that the person creating the power of attorney understands the nature and consequences of the document being signed. This can be achieved by requiring the witnesses to certify, in writing, that in their opinion, the grantor was mentally capable of personal care at the time the document was signed. These witnessing requirements...would serve to impress upon the witnesses the gravity of the situation and hopefully dissuade those who might consider abusing the power. Although these safeguards will cause inconvenience to grantors, they should not prevent the power of attorney for personal care from being a practical tool for the making of 'authentic' substitute decisions."

So removing that requirement runs directly contrary to the recommendations of the Fram report.

Hopefully, in the light of these comments and the comments of other presenters, the committee will seriously consider an amendment to reinstate the witness requirement and thereby uphold the integrity of the Substitute Decisions Act. Thank you.

**The Chair:** Thank you, Mr Winninger. We only have about 30 seconds per caucus,

**Mr John L. Parker (York East):** On the subject of a single assessor acting alone, the qualifications imposed in the statute for that assessor strike me as quite similar to the qualifications of your average judge. Judges lock people up in jail every day of the week and give them a criminal record and they do that acting alone. Why isn't it appropriate for an assessor who's similarly qualified to act alone?

**Mr Winninger:** Judges usually rely on expert evidence, and I'm not sure that the quality of expert evidence that is placed before a judge is always placed before the Consent and Capacity Board. Simply because these boards are convened on, I think it's a maximum of six days' notice or so, and it might be two days into that notice period before the patient is even able to make contact with a lawyer, and you can't always get adjournments—for that reason I don't know that the comparison is entirely a valid one.

**Mr Dwight Duncan (Windsor-Walkerville):** You commented about the Lightman report and I believe there were 104 recommendations in that report. I just assume that you're implying that somehow the Advocacy Act addressed even a portion of those recommendations. My experience was that it wasn't the case and that the Advocacy Act didn't in fact respond even to 10% of those.

**Mr Winninger:** I didn't mean to suggest it was the Advocacy Act that responded to those recommendations. What Ernie Lightman did was highlight the plight of vulnerable people, while the Residential Rights Act—

**Mr Duncan:** Yes, but I guess the point I'm making is they really weren't responded to. None of the—



**Mr Winninger:** The Residential Rights Act passed by the NDP government, I think it was Bill 120, did respond to—

**Mr Duncan:** Not in its entirety.

**Mr Winninger:** Not in its entirety, but there's a lot in there and certainly this government should take a look at the report and—

**Mr Duncan:** In fact, they didn't respond to the vast majority of the recommendations and vulnerable people in those institutions are still very vulnerable because of the failure to act on that.

0920

**The Chair:** Thank you, Mr Duncan.

**Mr Winninger:** I agree with you.

**Mrs Marion Boyd (London Centre):** Thank you very much, David, for coming. On this issue that Mr Parker raised, the burden of proof in a court of law is much higher than it is in front of a review board. We're talking about beyond a reasonable doubt and we're talking about that beyond a reasonable doubt with what is presented before the court and no other evidence. Consistently, our colleagues keep talking about this as being a comparable situation. It certainly isn't, is it?

**Mr Winninger:** Certainly in a criminal case the test of proof is proof beyond a reasonable doubt and that may be the kind of case that the member for the government was addressing, but as I said—

**Mrs Boyd:** He said sending to jail, so obviously it was.

**Mr Winninger:** Yes. Even on a reasonable burden of probabilities there just isn't that level of expertise before the board. That's why it's so necessary, I think, that if there is going to be one member sitting on the panel, which I don't agree with—but if there is going to be one, then I think that one member should have some expertise in evaluating capacity. I don't think the ordinary lay-person off the street should be sitting in judgement of another person's capacity, especially without adequate safeguards.

**The Chair:** Thank you, Mrs Boyd. Thank you, Mr Winninger, your time is up. We appreciate you attending this morning.

#### BRANTFORD AND DISTRICT ASSOCIATION FOR COMMUNITY LIVING

**The Chair:** The next organization on our agenda is the Brantford and District Association for Community Living. Please could you identify yourself for the purpose of Hansard and then you may proceed. You have 20 minutes.

**Mrs Eleanor Moore:** Eleanor Moore from Brantford, Ontario. We represent the parents' action committee of the Brantford and District Association for Community Living and are interested in the rights, health and safety of individuals who are developmentally challenged. From the Brant county area alone, we represent approximately 250 individuals who are developmentally challenged, including our own sons and daughters, and 130 members of the association in the county.

People who are developmentally challenged used to be called mentally retarded. Whatever the label, they are

individuals who represent a broad range of competency, all of whom need some type of support for daily living skills. Some require 24-hour support while others, at the other end of the continuum, may require very little support.

We ask that this committee recognize this special group of people who are developmentally challenged as having special needs throughout their entire lives. While wishing to allow these individuals the right to make decisions based on their individual level of cognitive understanding, we also want you to recognize that the majority of developmentally challenged individuals will require support to problem-solve and make decisions all their life.

Under present law, the only avenue available for these individuals to receive the support they require is for parents or family to go through the courts and have them declared mentally incompetent. This is not the solution. Parents and family need to be recognized as having the right to support a person who has the diagnosis of mental handicap in making decisions. This is extremely important in financial matters, health and medical decisions and daily living.

With current systems, we as parents often struggle to be recognized as having the right to answer or sign forms and generally make decisions with our developmentally challenged sons and daughters who are adults. In some cases, we need to be recognized as the substitute decision-maker for them.

We worry about the future when we are no longer here and are concerned about those individuals who do not currently have any family to advocate and assist them. Parents and individuals need to be able to identify another person or an agency, such as the association for community living, to act as a support in decision-making for an individual who is developmentally challenged. That person or agency would have the capacity to render a supportive role for the handicapped adult in problem-solving, or in some cases may need to be recognized as the substitute decision-maker.

Having a power of attorney is the next best alternative. However, the current system relies upon a lawyer's opinion as to whether an individual is capable or not of understanding what a power of attorney is. All individuals who are developmentally challenged would need support from family, friend or an agency to go through the process of establishing a power of attorney. The family, friend or agency would need to be accepted firstly as a support person for the decision-making process, or secondly, as the substitute decision-maker. The power of attorney is a more acceptable option than having a public trustee or guardian assigned who may or may not understand the needs of the developmentally challenged individual.

Substitute decision-making and consent for treatment are issues that affect this population currently because of negative attitudes and misinformation about individuals who are developmentally challenged. They should not have to be declared incompetent or incapable because of their disability. There is an ongoing need to support these adults in problem-solving and family are the best people to do this as we are the ones who know them and care



for them. When family can no longer support our sons and daughters, we need to ensure that someone, or an agency that will care, will maintain this supportive role.

We strongly encourage you to ensure the rights and dignity of individuals who are developmentally challenged through Bill 19. Please address our issues regarding the lifelong need for support by individuals who are developmentally challenged and the fact that the need is unique to each individual. Our concerns for our sons' and daughters' financial security, health and safety, as well as acceptance as citizens, are necessary to remember in all considerations and deliberations regarding Bill 19 by this committee.

In summary, we feel that a method must be created to allow the parents or siblings and individuals who support the adult with a developmental challenge be recognized legally as an advocate and, in some cases, with the power to sign consent. If a mechanism can't be designed to meet our wishes then a far more user-friendly and less costly power of attorney be created that would recognize parents or siblings and the agencies that are the caregivers.

Lastly, the designation of incompetent and the use of the public trustee should be the very last resort.

We look forward to having our concerns regarding these persons addressed in a manner that will not only ensure that their best interests are maintained, but will also recognize family as support decision-makers. Thank you for your consideration.

**The Chair:** Thank you, Mrs Moore. There may be some questions. Each caucus has three minutes and we'll start with the opposition.

**Mr Duncan:** Thank you for your presentation. Families of developmentally challenged individuals, in my experience, are very concerned especially where there is not necessarily going to be support after the primary caregiver or support person is gone. Is it fair to say that's part of what you're relating to here today?

**Mrs Moore:** That is part of it, yes.

**Mr Duncan:** Another question I wanted to ask, because I'd like to get this on the record at committee hearings: Are you familiar with the health and safety orders that have been issued against the Windsor community living association?

**Mrs Moore:** No, I'm not.

**Mr Duncan:** Basically they're suggesting the use of guidelines that would allow the use of restraints and so forth, in community living facilities. We've asked the Minister of Labour to intervene and provide conciliation and they've not yet responded.

But I wanted to ask you—back to this then, if you're not familiar with those orders—in your view, can you spell out any specific changes you would make to make this bill more acceptable or that would address your concerns in a more complete fashion?

0930

**Mrs Moore:** Well, personally I feel that if a person has the medical diagnosis of mental retardation, developmental challenge, whatever label we want to put on it nowadays, they would be able to have a form that would allow them to have parents or an agency act as their power of attorney, I guess—

**Mr Duncan:** Their trustee.

**Mrs Moore:** —their trustee without having to have them declared mentally incompetent, because many of them just need that support and the way you explain things. Parents, families or the agency that they're dealing with know how that particular person understands things, how you have to present them to that individual for them to understand, where lawyers or whatever don't understand that, by and large.

**Mr Duncan:** Your organization has identified, I'm sure, organizations and others that would be in a position to provide that kind of a trusteeship for members and their families.

**Mrs Moore:** At this point, because it's the developmentally challenged we are dealing with, we have only recognized the Association for Community Living, but I presume there are other agencies too.

**Mr Duncan:** I can tell you in an agency I used to run we were asked on numerous occasions if we would agree or consent to become a trustee—unfortunately, we weren't able to because of the difficulty and the commitment involved in that—where there was an adult whose primary caregiver didn't have anybody to succeed them, in effect. I think that's very prevalent.

**Mrs Boyd:** Thank you for your presentation. I think, in fairness to Bill 19, it's really important for us to recognize that the purpose is to have the public guardian and trustee as the last-resort trustee. I think the changes make it even clearer, although that was the intention of the previous legislation, that where there are family or friends who are trusted and able and willing to make decisions, they ought to be able to do that. I think the bill makes that process much easier and much less expensive for people than it was.

I think everybody appreciates the issue you raised about the sensitivity of the issue of incompetency or incapacity and what that means to people, because we've had a lot of people come before us and talk about how that feels. We understand that. On the other hand, in law the only time we want someone else to be authorized to make decisions on our own behalf is when we clearly are unable to do so. I think the language is frankly the legal description of how we make that decision that someone is unable.

Would you agree that many of the people you work with might be able to make decisions in some ways, possibly about areas of their own personal care, as opposed to property or as opposed to money?

**Mrs Moore:** Definitely, yes.

**Mrs Boyd:** The sensitivity around this is that there are two different kinds of powers of attorney and a good deal of flexibility in terms of the conditions under which people can exercise that care, so I think some of your concerns may have been met by the current legislation. It'll all depend on whether the processes and the administrative way in which it is carried out deal with that.

I also am interested in your concern round an association or an agency being able to assume this ability to look after people. There have been some concerns around the issues of conflict of interest that might occur, particularly if someone were also employed by that agency or where that agency was a primary caregiver for the person. Have you any comment on that?



**Mrs Moore:** Yes, I'd like to make several comments actually, but I'll start with that one. As a parent, I wouldn't feel that there was a conflict of interest, and if there was, it would be to my daughter's advantage to have someone who worked for the association or was employed by the association be the substitute decision-maker. I think that's basically what we're looking for, rather than someone out there in the community who knows nothing about our sons or our daughters or how they function.

If I could comment on the first part of your remarks, what we are finding with doctors and hospitals and even dentists is that they're saying, "Okay, this person is an adult, so I have to deal with them." Many, many times parents are just excluded. They're told, "Get out, because this person is an adult." We're really concerned, especially in the medical and safety issues, that this is going to result in dire consequences.

**Mr Ron Johnson (Brantford):** It's good to see you again, Mrs Moore. I want to thank you for the last time we met, in Brantford, because there's a great deal to be learned by talking to people who are directly involved. Unless we, as government, actually listen to the people who know the situations and what it's like to live with this kind of thing, we're not going to be making very good decisions without the kind of guidance that we get from people like yourself.

There's a comment you made here that I found to be pivotal in the presentation. I'll just briefly read it. It says: "There is an ongoing need to support these adults in problem-solving, and family are the best people to do this as we know and care for them." I think that's very, very important because that really is what this legislation is for. It's about empowering family members again and taking the lawyers and the paid advocates and the rights advisers and all those people who would be complete strangers to you, to try to really pull them out of situations where family is there. I think, though, we have to recognize that there are times when vulnerable individuals don't have the family supports that a lot of the people with your association are lucky to have. I guess my question would be, what sort of thing do you see happening for those who don't have the type of family support? What kind of mechanisms would be in place for those kinds of people, do you think, that we could foster in communities?

**Mrs Moore:** I would hope that there would be an agency that would pick up that slack, as it were. I think there are very few people out there who are developmentally handicapped who are not connected with some agency. They may not be the agency that can assume that role but can direct them to an agency that can assume that role. I don't know whether we made it clear in our presentation or not, but I guess really what we're asking is that there be a portion of this bill that is directed directly at the developmentally challenged adult, giving doctors, dentists, lawyers, all those people, a clear direction that this person has been diagnosed with this diagnosis and so this set of rules applies to them.

**Mr Ron Johnson:** I want to just—

**The Chair:** Thank you, Mr Johnson. I believe your time is up.

**Mr Ron Johnson:** That was quick.

**The Chair:** Mrs Moore, we thank you for expressing your concerns to the committee today.

**Mrs Moore:** Thank you for allowing us the time.

#### LONDON BATTERED WOMEN'S ADVOCACY CENTRE

**The Chair:** The next person with a submission is Cheryl Champagne, of the London Battered Women's Advocacy Centre. Good morning. Welcome.

I'd like to take this opportunity to welcome Robert Wood, the government member for London South, to the committee. Good morning, Bob.

You have 20 minutes, including questions. Please proceed.

**Ms Cheryl Champagne:** Good morning. In April 1995, I gave a presentation to the Ontario Advocacy Commission on the issues of violence against women and the escalated risks for women who are further marginalized by a disability or aging. I spoke of the increased risks of HIV or AIDS for women who are victims of violence. I also spoke of the additional oppression for immigrant or minority women, first nations women and lesbians who are abused by their intimate partners and face systems that do not respond to their needs. I recall being very impressed by the diversity and the calibre of the people involved with the Ontario Advocacy Commission and pleased that they were mandated to provide not only individual advocacy, but systemic or institutional advocacy as well. This meant that changes could happen that would benefit everyone, not just a select few.

The political climate has changed a great deal since that time and one of the major thrusts by this government has been to make "advocacy" a bad word. This government states advocacy is too costly. At the London Battered Women's Advocacy Centre, when people's fundamental rights to safety and dignity are at stake, we believe anything less than advocacy is too costly.

Change is not neutral. There are many sweeping changes that are being made to our province's institutions, all under the guise of fiscal management. Every day we are being told that social programs are to blame for the deficit. In fact, as a percentage of government spending, costs for social programs have decreased, ironic really when you think of the tens of thousands of Canadians who are unemployed now who were not a decade ago. One would think the cost of social programs, especially given what we've been told about spending on general welfare and unemployment insurance, would have increased. In fact, between 1992 and 1993, as a percentage of the gross domestic product, social spending represented 17%, compared to 19% in 1975.

The people of Ontario are being hard hit by changes in polity direction, but let us be clear that things not being equal, there are some people who are being harder hit than others. Statistics Canada shows that between 1987 and 1983 the richest 30% of families' share of wealth grew by \$7.12 billion while the bottom half of Canadian families lost \$7.3 billion. The rich cannot get richer without taking from the less-well-off. Is this what is meant by a free market economy?



Who are the less-well-off? They are the people branded as special-interest groups: people with disabilities, the aged, women, immigrants, refugees, first nations people, people who have HIV or AIDS. If they are somehow able to speak out, they are the people whose voices are discounted. This is why the Advocacy Act and the Ontario Advocacy Commission, which your government is eliminating with Bill 19, are so important.

**0940**

The Ontario Advocacy Commission was mandated to address both individual and systemic advocacy, to hear and act on behalf of individuals who could not do so for themselves, to attempt to find solutions for their needs. Bigger than that, they had the mandate to advocate for change at the systemic level so that problems could be eliminated in the long term. This government, then, is not only eliminating mechanisms for assisting individuals, but also ways and means of achieving long-term structural solutions.

Since this government's election, we at the London Battered Women's Advocacy Centre have felt an increasing resistance to the concept of advocacy. Simply, the word "advocacy" means acting on behalf of others who are not able to do so for themselves. We listen to the voices and experiences of battered women and assist them to try and end the violence that they are being subjected to in their lives. When we hear over and over again of the systemic barriers that continue to endanger women and give their partners more power, we try and do something about it. We do not want to have an endless conveyor belt of battered women. We want violence to end. This is what we mean by advocacy.

Groups working together to advocate for change have been able to positively affect the lives of many individuals in our communities over the past 20 years. As part of the London Coordinating Committee to End Woman Abuse, the London Battered Women's Advocacy Centre has worked with the police, children's aid, school boards and others to end violence in our communities. As a result of these relationships and advocating together, we have been able to effect change motivated by social justice. An example in London is that our police department was the first to lay charges in woman abuse cases, a policy that is now province-wide. It is by listening to collective voices and advocating for this kind of systemic change that we are accountable to the women we work with.

Ending violence makes sense at many levels. There are the human costs, the pain and suffering, the loss of potential that no one can put a price tag on. There are the children who grow up witnessing violence, boys who are 10 times more likely to become perpetrators and girls who are less likely to leave abusive relationships as adults, compared to children who have not witnessed woman abuse. A recent study by the Centre for Research on Violence Against Women and Children calculated the financial costs of violence as being over \$4 billion. As the pendulum swings from social justice spending to tax breaks for the wealthy, the human cost factor will no doubt increase.

The Advocacy Act creates a commission that is positioned to enhance social justice for individuals and

groups while decreasing long-term costs due to systemic problems. The elimination of the Ontario Advocacy Commission and other cutbacks to other advocacy groups limit and weaken the ability of marginalized groups to participate in public debate and policy development.

Our special interest, ending violence against women and ensuring justice for all people, is in the public interest. Our public interest represents more people than the business elite who earned billions of dollars while benefiting from billions of dollars in tax deferrals. Without advocacy and legal protection, vulnerable people can be taken further advantage of and suffer more than their share of the so-called collective pain we are told we must endure to get our province financially afloat.

According to the figures from the Council of Canadians with Disabilities in 1985, disabled women between the ages of 15 to 64 had a median employment income of over \$8,000 as compared to \$10,000 for disabled men, over \$19,000 for non-disabled women and \$21,000 for non-disabled men. Over 60% of disabled women were not in the workforce. The other option for people is social assistance. Recent statistics figures show that between 1985 and 1990 the percentage of all disabled Canadians on social assistance went from 5% to 12%.

It is not surprising that people with disabilities are hardest hit. When unemployment is rising and employers have a vast labour pool to choose from, they are not willing to pay the costs associated with having an accessible workplace for an individual with a disability. With the recent elimination of employment equity, people with disabilities will continue to be marginalized in the workplace. Companies are driven by profit, not social or economic justice. It is the government's responsibility to ensure social and economic justice. It is the government that is elected to represent all of its people, to advocate on our behalf.

The disparities for people with disabilities are alarming. They are much more likely to live in poverty and they are much more likely to suffer violence at the hands of those who are designated to care for them, whether they are family or professionals. In 1991, the Canadian Panel on Violence Against Women stated that in order to end violence against women we needed to promote economic equality for women. In fact, with the erosion of housing, social services and child care, fewer women are able to leave abusive partners, and women with disabilities are even less able to do so.

What we want and expect from our government is accountability and fairness. This is a huge undertaking and the reason laws and systems are created to do the job. Many of the laws being eliminated or changed by this government are effectively dismantling structures designed to ensure equitable treatment and accountability. The point I cannot make often enough is that advocacy is a necessary activity for ensuring the responsiveness, accountability and effectiveness of our systems. The goal of advocacy is to do ourselves out of business, not stay in it, and in the long run save lives and of course money. The government is in the position to be the most powerful advocate for change.

Let me share with you some of the information I gave to the Ontario Advocacy Commission last year. This



information is important with respect to ensuring that checks and balances exist in the Consent to Treatment Act and the Substitute Decisions Act.

Women with disabilities are much more vulnerable to violence. Statistics from DAWN Canada indicate that of the over one million women with disabilities in Canada, over two thirds have been physically assaulted by the time they reach puberty, and one in three of these women will experience sexual and physical assault as adults, double the number for women without disabilities. Women with disabilities often rely upon others to care for their wellbeing, physical, emotional and financial.

Women who live in fear of violence are much more likely to alter their behaviour to avoid abuse, such that they do not voice their needs, preferences or opinions if they are in opposition to abusers. Bill 19 is removing safeguards in the Substitute Decisions Act, thereby giving more power and control to caregivers. With Bill 19, a witness is not obligated to state whether they believe the grantor to be incapable of giving another person the authority to make decisions for them. It is not uncommon, in abusive relationships, for abusers to try and paint a picture of the victim being incompetent to prevent themselves from being identified as abusers or from losing the benefits from having power over another person. Whether the person is an intimate partner, family member or a professional, giving someone more power with less accountability will put a victim of abuse and any vulnerable person at further risk. Bill 19 even gives substitute decision-makers the authority to approve shock treatment for another individual which, frankly, I find quite frightening.

With regard to consent to treatment, Bill 19 eliminates all requirements that rights advice or notices respecting rights advice be provided to persons who are found by a health practitioner to be incapable of making decisions for themselves. Again, the elimination of rights advice removes the extra safeguard for those who cannot speak for themselves. The Ontario Advocacy Commission makes a good point in saying that just because a right is there in the law, it does not mean that those who are marginalized or pressed are going to know about it. Every day at the London Battered Women's Advocacy Centre, women tell us how their abusive partners told them they would not be entitled to custody of their children or to financial support or equalization. That is not the law. It is in the abuser's best interests to misinform and therefore disempower a victim of abuse. The end result is that victims do not take action for themselves, as they believe they have no recourse. This is why rights advice is needed, and what we mean by advocacy. Battered women tell us that it is not safe for them to speak to their family members or friends, that they come to us because we provide confidential and professional assistance.

We have additional concerns about the way some individuals will be marginalized or discriminated against. Bill 19 excludes gay or lesbian partners from participation in their partners' needs or decisions. Family members who have a rank on the list of substitute decision-makers could make decisions on the basis of their own value system, versus the wishes of the individual, to include their intimate partner.

Bill 19 states that a language barrier or disability is not a reason to prevent emergency care, although reasonable steps must be taken to locate somebody who could provide this service. In London, the Cultural Interpretation Service that provides interpreters who are trained in crisis intervention is losing its funding. We are told we must rely on family, friends and community volunteers to do this work. It is most likely that a battered woman who requires emergency treatment at a hospital will be accompanied by her batterer. Without trained professionals to do this work, women are being put at further risk. Abusers are unlikely to tell the truth about the source and extent of the injuries.

#### 0950

We have a situation where the act is setting out provisions for people when the services simply will not exist. The same has occurred with the Victims' Bill of Rights, where it states that victims of crime should have access to information about services. Again, not only are there no provisions to ensure victims get the information and learn of their rights, but many of the services are being cut back as well.

We are also concerned about the changes to the requirements of a panel making decisions about capacity. Bill 19 eliminates the requirement that at least one member of the panel must have expertise in evaluating capacity. We are concerned about a panel making these kinds of decisions without the expertise to do so. Has accountability once again been sacrificed for money? Would you want a panel of dentists to decide if you were to have heart surgery? Would you go to a real estate agent to give you advice on having your car fixed? This does not make any sense.

Unemployment, employment equity, housing, violence and abuse, social spending, interpretation services, victims' rights; you might be asking what all of these things have to do with consent to treatment, substitute decision-making and even advocacy: Everything. We live in a complex society where people's access to resources and information determines how much power they have. Bill 19 is completely about giving individuals power over other individuals who may already have little or no power. That is why the three systems and original acts are needed to work together.

I want to close by reiterating my point about advocacy. Advocacy is not neutral. Change is never neutral. What this government is doing by eliminating the Advocacy Act, and by design the Advocacy Commission, is ensuring that there are no roadblocks for the kinds of changes it wishes to make. There are sweeping changes being made that are influencing the daily lives and liberty of many Ontarians, Ontarians who will now never be heard. The Advocacy Act is a product of over a decade of work with all three political parties and many individuals and advocates from communities across the province. We are not only saddened by the loss of this progressive step, but as taxpayers we are also alarmed by the valuable investment of money, time and expertise that is being wasted and thrown away.

We are told over and over again that the changes are necessary, that they are for the future of our children. Do we not have children with disabilities? Will not we and



our children grow old? Is it necessary that the financiers get rich on the backs of the poor, the disabled, the elderly, the disenfranchised?

Advocacy is a good thing; it is a responsible thing; it provides the knowledge of hearing the voices of many; it is long-term planning to promote social justice and save on both the economic and social costs. It is your responsibility as a government to advocate for those who do not have power, not those who do.

Individuals need advocacy to inform them of their rights so they can make decisions for themselves. Advocates turn to you, our government, to share what we have learned and to ask for social justice and change. When there is nowhere to turn, when we are told that justice is too expensive, we ask, if not now, then when?

**The Chair:** We have two minutes each. We start with Mr Marchese.

**Mr Rosario Marchese (Fort York):** Thank you for your presentation. You made a number of important points. One that stands out for me is, "It is your responsibility as a government to advocate for those who do not have power, not those who do." Part of my concern around this is that when you eliminate advocacy, the commission and the rights advisers, you're really removing yet one more element that could be there to support people who have no family or where the family is incapable or where the family may be abusive in some cases. That's what the Advocacy Act, in my view, did and the rights advisers do in terms of getting to the people who otherwise will have no one to turn to. They're not a solution, they're not likely to find the abusers everywhere, but they're yet another element that is there to protect the most vulnerable people.

This government is obviously committed to repealing the Advocacy Act, and it seems it wants to find other forms of advocacy that already exist in society to solve the problems we're talking about. I'm not sure; do you have a sense of what else we can say to defend advocacy, to defend rights advisers?

**The Chair:** Thank you, Mr Marchese, your time is up. Mr Clement.

**Mr Tony Clement (Brampton South):** Thank you for your views. Just for the record, when I read *Shooting the Hippo*, I derived different conclusions than yours, but perhaps we have different perspectives.

I did want to talk a bit about what you said on page 1, though. I just wanted to say, to alleviate some of your concerns, that we as a government are not determined to make "advocacy" a bad word. In fact, deriving our point of view from the O'Sullivan report, we think advocacy is a critical and moral duty. This is not just about dollars and cents; this is about individual moral duty to advocate. We all have this moral duty, I believe, to advocate on behalf of those who are vulnerable in our society.

I guess what I want to get some feedback from you on is, we just don't see institutional advocacy, hired rights advisers by an Advocacy Commission, as the way to go. We want to push down advocacy to friends and loved ones and your organizations, which have been very successful and very outspoken, if I can put it that way, in terms of your advocacy, in terms of systemic advocacy as

well. Do you think that we're entirely on the wrong track that way?

**Ms Champagne:** As you know, we work with women who have been abused by their intimate partners and family members, so the concern about downloading the responsibility to individuals in the community is that there is no accountability, then, for those individuals and that vulnerable people are at much more risk of being harmed by people they know than people they don't know.

**Mr Ramsay:** Thank you very much for your presentation. There are a couple of things that stand out from your presentation. I share your concern in regard to rights advice, that if there is the mechanism in the act, you can appeal the decision. I would think at the very least that the person should be informed of their right to appeal that decision of incompetency.

The other thing—I just want to get a clarification—because the way I read the act in regard to who can give consent, in section 18 it's basically a hierarchy of people. It starts with a person's guardian, a person's power of attorney designate, a representative just for health treatment, and then it says the incapable person's spouse or partner. So it seems to me it leaves it open.

**Ms Champagne:** It actually says "as per the Family Law Act."

**Mr Ramsay:** No, it actually doesn't in section 18.

**Ms Champagne:** It doesn't?

**Mr Ramsay:** No, it does not. I just want to bring that to your attention, because I'd feel comfortable with that.

**Ms Champagne:** Oh, good. Thank you.

**Mr Ramsay:** I just wanted to say that if you still felt there was something there that bothered you, then I'd like to see it.

**Ms Champagne:** Okay. No, what I read, I thought it was in the act.

**Mr Ramsay:** But the way I've got it, I could show you that in a second, it looks like it's all right there.

**Mrs Elinor Caplan (Orlène):** On a point of order, Mr Chair: I think it's really important that when someone comes forward with a legitimate concern where the act clearly addresses that concern, there's an obligation of the person with carriage of the legislation to point that out to the individual, because then he or she would leave less concerned and frustrated. That's what carriage of a bill is about. I know that we have new members, but I had expected Mr Parker, who has carriage of the bill, to use their time to inform this person instead of hearing a paternalistic pontification from Mr Clement. Frankly, I was very disappointed in the government's response to this.

**The Chair:** Excuse me, Mrs Caplan, I think—  
*Interjections.*

**The Chair:** Hold it.

**Mr Parker:** If I corrected every misconception that has come before this committee, we would be here all day listening to me lay out my corrections.

**Mrs Caplan:** That's why you are supposed to carry the bill; that's why you're here.

**The Chair:** I think that's out of order. If we may proceed, we now have the Persons United for Self-Help in Southwestern Ontario, Bonnie Quesnel.

*Interjections.*

**The Chair:** Could I have some order here, please. We do have to move along.

**Mrs Caplan:** We shouldn't have to carry the God-damned bill.

**The Chair:** Excuse me. Ms Quesnel?

*Interjections.*

**The Chair:** Could I have some order. I don't think this is fruitful. The point's been made.

**Mr Duncan:** Chair, come on, can't you control this?

**The Chair:** It's very difficult sometimes. We are using the time of the good people who have appeared before us.

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#### ACTION LEAGUE OF PHYSICALLY HANDICAPPED ADULTS

**The Chair:** We are going to proceed to—well, it's not the Action League. I thought that changed.

**Clerk of the Committee (Ms Donna Bryce):** The Action League is going at 10 o'clock because Bonnie's still waiting for her briefs to arrive.

**The Chair:** Okay, the Action League of Physically Handicapped Adults. Could you identify yourself? Is it Jennifer Wilcox?

**Dr Shirley Van Hoof:** No. I'm Dr Shirley Van Hoof. If you have my brief in front of you, you'll see that myself and Patti Doolittle will be doing the presentation. It looks like this.

**Clerk of the Committee:** If I could explain, Bonnie's briefs are arriving a little bit late, so she agreed to go at 10:20 and the Action League agreed to go at 10 o'clock.

**The Chair:** I'm very sorry for the confusion. If you would proceed.

**Ms Patti Doolittle:** I'd just like to introduce myself. I'm Patti Doolittle, the chairperson of ALPHA, and this is Dr Shirley Van Hoof, the treasurer. I'll start off.

The Action League of Physically Handicapped Adults over the last 25 years has worked for the improved quality of life for persons with disabilities. This includes all the aspects of life that affect all people. After all, we are people too, with extra challenges.

ALPHA believes that Bill 19 will impinge on the rights of vulnerable people and it perhaps even violates the Charter of Rights and Freedoms.

And just a little extra thing, for the past 25 years, ALPHA has been a subcommittee of the March of Dimes of southwestern Ontario.

**Dr Van Hoof:** Thank you, Patti.

The rush to pass this extensive bill is disconcerting. I have only examined parts of Bill 19, and only a few direct examples of potential problems have been noted. The government needs to have a full assessment done of the impact of this legislation on real people before moving ahead. The goal should not be to change legislation so you can make it your own but to change legislation to make it serve the citizens of this province better. Bill 19 will not serve Ontario citizens well.

ALPHA believes that in Canada, and thus in Ontario, all political parties support the protection of the human rights of all citizens. This is supported by history. On December 5, 1989, as recorded in Hansard, MPP Dianne

Cunningham of the Progressive Conservative Party encouraged the governing Liberals to proceed with an advocacy program. She noted the need for independent advocates for vulnerable adults. Then the New Democratic Party took office and, after due consultation, the Advocacy Act, 1992, the Substitute Decisions Act, 1992, and the Consent to Treatment Act, 1992, were passed into law.

Now the subject has become a political issue. We need you to refocus and fulfil the purpose of the aforementioned legislation, which is to enhance the dignity, autonomy and independence of vulnerable people.

Bill 19 threatens to undermine or eliminate the progress that has been gained over the last 15 years. We believe that parts of the bill may even violate the Charter of Rights and Freedoms.

Contrary to misinformed press reports, the Advocacy Act, 1992, provided assistance to vulnerable adults so that they understood their rights and could express their wishes if they had difficulty doing so on their own, for whatever reason. The act supported the development of strong family relationships, where possible. The act specifically required advocates to encourage the involvement of the family. However, if the family/caregiver was abusive, an advocate could have supplied support to assist the person to find other living arrangements in the community.

Bill 19 does not seem to have the same balance of facilitating family involvement yet keeping the safeguards in place to deter abuse of the vulnerable person. Bill 19 has the potential of enhancing the powers of those in charge while weakening or removing fundamental rights to which vulnerable people are entitled. The advocacy resource centre of London that made the presentation just prior stated this very well and I support that presentation.

Examples of concern—and I hope you're familiar enough with the bill that these make sense, because taken out of context, as they are, and presented to fellow people that I know, it's very confusing for them, but I hope you can grasp this. The first one is Bill 19, part III, subsection 16(4), and I've noted on page 5. The ones I could find, I put the page for you:

"(4) The assessor shall ensure that copies of the certificate of incapacity are promptly given to the incapable person and to the public guardian and trustee.

"(5) As soon as he or she receives the copy of the certificate, the public guardian and trustee is the person's statutory guardian of property.

"(6) ...the public guardian and trustee shall ensure that the person is informed...

"(a) the public guardian and trustee has become the person's statutory guardian of property; and

"(b) the person is entitled to apply to the Consent and Capacity Board for a review of the assessor's finding...."

This flies in the face of "all persons shall be assumed capable." It is unthinkable that a third party can request a person be assessed and the person does not have any advice or protection before the certificate is issued. Only after the fact can the person begin to try to clear the record.

Guilty until proven innocent? I can't express how angry this whole thing makes me, because someone can ask that I be assessed. The assessor doesn't have to tell



me anything about the assessment. They can go ahead and do it, and then I have to prove that I'm capable. That's wrong.

In the explanatory notes, and it quotes part II, section 16 of the new act—I couldn't find it in the papers that I had, but it states that, "The new act removes all references to rights advisers and eliminates all requirements that rights advice or notices respecting rights advice be provided to a person who is found by a health practitioner to be incapable with respect to a treatment."

This is appalling. Even criminals have their rights read to them. The consequences of this have not been thought through.

Explanatory note 11—it states it's part II, subsection 27(6) of the new act; again, I couldn't find it in my papers—states:

"Although statements by family members are not required by the new act, health practitioners are permitted to rely on assertions made voluntarily by anyone who gives or refuses consent to a treatment on an incapable person's behalf."

This assumes that the person speaking on behalf of the patient has their best interests at heart. In this day and age, I would sooner rely on the health professional's goal to "first do no harm," as the likelihood of secondary gain by the health professional is less than that of a relative.

My uncle can show up at the emergency room and tell the doctor, "Yes, I want this treatment," or "No, I don't want this treatment," if I can't speak for myself. You don't know who he is, and you assume that he likes me, or that he isn't going to inherit my millions. There are a lot of assumptions here, and this is made into law. What right do I have?

Explanatory note 17, part II, section 29 of the new act, states:

"The new act provides health practitioners and substitute decision-makers with protection from liability not only in respect of decisions concerning treatment of an incapable person but also in respect of decisions concerning admission of an incapable person to a facility for the purpose of treatment."

This attempt by the government to allow persons in positions of trust to avoid responsibility for their decisions is unreasonable. Each decision may have dire consequences for the family of the affected person as well as the person themselves, so care must be taken to be sure each decision is thought out. This will only happen if the decision-maker knows they will be held responsible. People who believe they are above reproach are more likely to abuse their power.

This again goes back to Bill 26. We give people power and then we say, "But they're not responsible." We give them blank immunity to anything. This is unprecedented power and unprecedented free-of-liability legislation. I have never seen this in my life.

1010

Part IV, section 75, section 8 of the act, page 57:

"(1) The public guardian and trustee may charge fees for anything done by the public guardian and trustee under this or any other act.

"(2) The public guardian and trustee shall establish the fees, subject to the approval of the Attorney General.

"(3) The fees may be calculated on a flat rate basis for each thing done, on an hourly basis, on the basis of actual costs incurred by the public guardian and trustee, as a percentage of the income or capital of an estate, or in any other manner that the public guardian and trustee considers appropriate."

These rules could be used to the person's advantage, or it could be used to decimate the person's estate. Once again, they have supreme power; they can do it any way they want. The person of the day, being the public guardian and trustee, could have a different way of figuring things and could take that person's estate and destroy it.

In summary, Bill 19 could be a very dangerous piece of legislation. After a very cursory review and only a few examples cited, I hope the government will look closely at this hastily crafted piece of legislation and have the consequences assessed thoroughly. The very essence of the quality of life and human dignity are at risk here, not only for the person but for their dependants, other family and friends.

For example, a single mother in a bitter custody battle with the father of their children is assessed at the request of her ex-husband by a doctor of his choosing. The mother and her children are at risk of mental destabilization as she fights to reassert her capability. Many unhappy scenarios could be played out, as she and her children have not had the benefit of advisers or lawyers right from the beginning of these proceedings. This is a nightmare.

I personally believe that this legislation will benefit lawyers much more than the people it is meant to protect. I regret that I did not have the time or stamina to do a more comprehensive evaluation of Bill 19. I trust that the great effort it has taken many of us to respond to the flood of government legislation will be respected and our comments and suggestions will be given serious consideration. Thank you for allowing me to appear today.

**The Chair:** Thank you. We have three minutes each.

**Mr Parker:** I want to respond to one point in particular. You said that the statute allows an assessor to declare someone incompetent without their knowing that the assessment's going on and without knowing the consequences. To satisfy you and for the purposes of the record, I want to read this in verbatim. This is section 78 of the bill. It's found on page 30:

"(1) An assessor shall not perform an assessment of a person's capacity if the person refuses to be assessed.

"(2) Before performing an assessment of capacity, the assessor shall explain to the person to be assessed,

"(a) the purpose of the assessment;

"(b) the significance and effect of a finding of capacity or incapacity; and

(c) the person's right to refuse to be assessed."

**Dr Van Hoof:** Why is that not where the beginning of this legislation stated—I think it's section 16. Why is it hidden in 78?

**Mr Parker:** You have to put it somewhere.

**Dr Van Hoof:** Yes, but why not with the legislation that is dealing with it to begin with?

**Mr Clement:** Page 30 of the legislation, ma'am. It's in the legislation.

**Dr Van Hoof:** They should be together.

**Mrs Caplan:** But it doesn't apply to evaluators. It's not evaluation for treatment purposes, to her finding of incapacity by an evaluator. An assessor for competency, yes.

**Mr Clement:** Mrs Caplan will have her opportunity, Mr Chairman.

**The Chair:** Mrs Caplan, you're—

**Mr Clement:** Point of order, Mr Chairman.

**Mrs Caplan:** Well, you're not exactly answering—

**Mr Duncan:** Point of order: That only applies, section 78—

**Mr Clement:** Point of order, Mr Chairman: The Liberals will have their time. I really must insist, Mr Chairman.

**The Chair:** Ladies and gentlemen, you seem to be rather grumpy this morning.

**Mr Clement:** I started off in a great mood, Mr Chairman.

**The Chair:** We have a number of grumpy people present today, and I'm just going to recess if this continues on. Mr Parker has the floor, and unless you have a valid point of order, please don't waste our time and waste the time of these people.

**Mr Marchese:** Mr Chair, may I recommend that, where necessary, we have civil servants here who could explain in a much more reasonable way, perhaps, aspects of the way this bill was drafted. You might want to call upon them quickly for a clarification.

**Mr Ramsay:** More accurately, too.

**Mr Marchese:** All right? Could you do that, Mr Chair? That would be helpful.

**The Chair:** Whose time is it going to be, Mr Marchese, yours? If that is your suggestion, I'll—

**Mr Marchese:** But if we're wasting time with the dialogue here and there, it's best to have them clarify as quickly as possible and move on.

**The Chair:** We're here for hearings, though.

**Ms Van Hoof:** But I would like clarification. If there is an explanation—

**Mr Marchese:** They would clarify.

**The Chair:** That's what we're trying to do.

**Mr Marchese:** They would clarify much more, perhaps less politically, and that would be easier and we could move on.

**Mr Clement:** On a point of order, Mr Chairman: We've heard insults from the opposition all morning—

**The Chair:** No, no, Mr Clement. That's not a proper—if we want clarification, we'll ask. If you're going to permit it, then the time is going to run and it's going to possibly be your time. Now, what was the question? We'll have a member of staff—

**Mr Marchese:** I think she knows what she has to say.

**The Chair:** Good.

**Ms Trudy Spinks:** In the existing Substitute Decisions Act, section 16 is the one that the presenter was referring to about statutory guardianship. It does say what Mr Parker just read into the record. The reason section 54 places it in section 78 of the bill is because the previous SDA didn't apply that to all assessments and it was felt that protection should apply to any assessment under the legislation, not just assessments under section 16. So it's put into the general category so that it applies to abso-

lutely any assessment that takes place by an assessor under the act, and not just those that are confined to statutory guardianship.

**Mrs Caplan:** Or an evaluator.

**Ms Spinks:** That's a different act. Evaluators are under the Health Care Consent Act.

**Mrs Caplan:** But does that apply to evaluators?

**Ms Spinks:** I won't speak for the Health Care Consent Act.

**Mrs Caplan:** Well, could somebody?

**The Chair:** Certainly. Could we have a comment on the Health Care Consent Act? Could you identify yourself, please.

**Ms Jutta Auksi:** My name is Jutta Auksi. I'm with the Ministry of Health. With regard to the Health Care Consent Act, if you're asking about evaluators, with respect to which kind of decision?

**Mrs Caplan:** The section that was just referred to that requires notice of an assessment of capacity: Does an evaluator have to notify someone that they're being assessed for the purpose of capacity for treatment?

**Ms Auksi:** Evaluators are not involved in consent to treatment. It would be a health practitioner. Evaluators are involved, for example, with admission to a long-term-care facility. With respect to admission to a long-term-care facility, there is a provision that rights to information relevant to that finding may be set out by regulation or could be done by policy of the long-term care—

**Mrs Caplan:** No obligation.

**Ms Auksi:** —and this is in the regulation-making authority. There is reference to that.

**Ms Van Hoof:** So it's very changeable.

**Mrs Caplan:** The same protection isn't in the statute as it is under the SDA.

**Ms Auksi:** Right. I could point out that the long-term care-policy area is working now with the placement coordination services for the institution of—

**Mrs Caplan:** But there's no statutory obligation for that consistency?

**Ms Auksi:** There isn't an obligation. There's regulation-making authority. That would be in the long-term-care facility statute.

**Mrs Caplan:** And what about obligation on professionals who are doing capacity assessments for the purpose of treatment, is there any obligation?

**Ms Auksi:** Again, that is within the scope of the regulation-making authority or could be done by policy—

**Mrs Caplan:** So there's no statutory protection under the SDA?

**Mw Auksi:** Not in the statute per se and not in the Health Care Consent Act itself. The regulation-making authority is under the long-term-care facility statute.

**The Chair:** Thank you very much. Our time is up. If we can—

**Mr Clement:** Mr Chairman, I think a lot of this dialogue has been very helpful but I'm not sure whose time it came out of.

**Mr Ramsay:** Everybody's.

**The Chair:** It came out of everybody's—

**Mr Clement:** I did wish to reply to her concern number 3, though, because there is something in the legislation which does alleviate her concerns.



**The Chair:** Unfortunately, if we're going to permit questioning of the staff, that will take up all the question time, Mr Clement, I can't see anything other. Thank you very much. Your time is up.

**Interjection:** Thank you.

*Interjections.*

**The Chair:** If this becomes an issue, we'll have a meeting of the subcommittee to discuss it, but I'm concerned that permitting individuals who are making presentations to ask questions of us or of the staff permits them to take control of this meeting, removes it from my authority, and the difficulty is that it could be a substantial delay. That's my position.

**Mr Marchese:** Mr Chairman—

**The Chair:** We will discuss it in the subcommittee if you want after.

**Mr Marchese:** Then you force us to respond, because what you have to do as a Chair is to use your discretion from time to time to allow staff to clarify. We don't want long debates—quick clarifications and we move on. That's a discretion you have as a Chair.

1020

#### PERSONS UNITED FOR SELF-HELP LONDON

**The Chair:** We have next, Persons United for Self-Help in Southern Ontario; Bonnie Quesnel. Good morning, Ms Quesnel.

**Ms Bonnie Quesnel:** Good morning.

**The Chair:** I understand we have your briefs now.

**Ms Quesnel:** Yes, you do.

**The Chair:** Good. You can proceed at any time. You have 20 minutes including any questions. Thank you.

**Ms Quesnel:** Persons United for Self Help is an organization which has been committed to working for advancement, integration and achievements of people with disabilities. We know the complications and difficulties which are faced by people caught up in the federal, provincial and municipal systems. These systems have lost the humanity and accountability that once protected the vulnerable. Rather than removing government from our lives and our decisions, this amended act will completely deprive us of our decision-making rights. Vulnerable people will become chattels for Ontario's already overloaded bureaucratic system. We will become pawns for brokers and paid caregivers.

Bill 19 ensures the loss of all independent advocates and rights advisers for us, the vulnerable. While we may still retain some rights, no one is obliged to tell us what they are. It's a little like having an expensive high-powered car but the instructions don't tell you how to turn it on. Like us, it's going nowhere fast. The independent advocate classification previously offered to us has now been corrupted into a playhouse for vested interest individuals/groups. An advocate should never benefit from their efforts for another. PUSH never has.

Agencies, officials, paid caregivers and experts are self-serving by nature. Their opinions are coloured by the political, social and economic bottom line, and not by human need. Their survival depends on adjusting their books to perpetuate their system and not in ensuring that people's needs are met.

This is not advocacy. These people, groups, do not always act in the best interests of vulnerable people. All this act does is simplify a means for bureaucrats to gain control over all aspects of a vulnerable person's decisions. PUSH already knows that the most vulnerable of society are being pushed, nagged, coerced or ignored into compliance. It is a tragic situation. We see it reflected in the insistent demands for "do not resuscitate" notations on our hospital files prior to taking our temperatures. PUSH members who recently sought medical support for correctable conditions, eg, hernia, bronchitis and bowel obstruction, have been asked for this DNR designation while receiving treatment.

What is even more horrifying is that if a person is tagged "incapable" no one has to tell them that their file is marked DNR. You, as able-bodied, working individuals will never be asked for this. You most likely won't be disabled and ill, frightened or in need of an impartial advocate like these individuals have been. System assumptions about your value and merit have ensured your wellbeing. Others are not so fortunate. The Latimer case has taught us that Canadian sympathies lie with the caregiver, not the victim.

Other problems we are currently seeing are:

Long-time tenants in supportive housing facilities are now being forced to sign a multipage legal contract without legal or rights advice under threat of service loss.

Individuals are being given the wrong prescription for their illnesses because assistance isn't available and no one takes the time.

People are being forced from existing community services into institutions because agencies decide and no advocate's there to speak for them or tell them their rights. There is no objective third party, only the paid caregiver's opinion. The paid caregiver may now support someone less troublesome, and because they have kept their ministry funding, nothing lost and everything to gain.

Family designated advocates are not a perfect solution either. We have seen the extremes. We know that some families nurture and assist and others hold on just to access the vulnerable person's pension dollars. There is yet another group who are caring and have no harmful intent but, because of years of being forced to sacrifice in a society that devalues their disabled child, they are fearful, overprotective and defer to professionals. It was the professionals who recommended, and families agreed, that disabled children and adults be institutionalized in facilities for the developmentally disabled and forced sterilization. Both have occurred in this lifetime and it can happen again.

We are hearing the words "quality of life" being applied exclusively to people who dare to get old, or to those with one or more disabilities. Their right to sustained health shrinks under the magnifying glass of some anonymous expert reciting antiquated positions on quality of life.

Regulated health professionals have the same self-seeking motivations as other human groupings. If Mr X is declared incapable, it will neutralize the validity of his complaints in the future. Besides, we don't have to tell him he's incapable.

A one-person appeal board is unreasonable. One person should not have all of the authority to judge capacity, appeal efforts or final outcomes. What's more, the elements used to determine capacity are not identified. Such limitations continue the system problems that people with disabilities and seniors know so well. The vulnerable won't be in the driver's seat of their lives. They won't even be able to ride in the back seat. As this legislation is now written, the vulnerable will be lucky to get a ride in the trunk.

Tell us what will happen when even more biased experts can decide who will get user-friendly focused care, or who is moved politely aside or committed to institutions? What will happen when no one truly is accountable to anyone?

Another great concern is based upon the fact that the former Advocacy Commission was empowered to note systemic problems. System problems, situations and difficulties arise repeatedly. In the absence of the commission, we are doomed to reinventing our solutions daily throughout Ontario. Our advocates will only be as good as their memory. There is now no likelihood for curative system change because there's no way to collect the data.

PUSH would recommend that instead of paying people with disabilities to stay at home, provide them with the authority, resources and salaries to advocate for themselves and each other.

The issues discussed here are very serious. They cannot be ignored. Please be responsible. Reconsider and change this legislation.

We need advocates and greater protection. Currently, this society allows us to participate only as burdens, not as resources. In your desperate need to gain control of fiscal problems, do not let history repeat itself.

Economic upheaval was the root cause and excuse for many shameful acts in this century. Society, which includes professionals and family members, has institutionalized, sterilized, denied rights to and denied independent living to people with disabilities. Such actions are wrong. When this is over you can go back to Queen's Park and you may deny these realities, but we live with them day to day and we cannot ignore them.

I thank you.

**The Chair:** Thank you very much. There will be three minutes per caucus.

1030

**Mrs Caplan:** Thank you very much for an excellent presentation. It's nice to see you again. I think you've raised a number of very important issues, particularly the one that you've raised which I haven't thought of quite as significantly, and that is that if a person is tagged incapable, in your words, by a professional prior to treatment they could turn to someone and get a DNR order put on their chart, and that someone could be from their family who has devalued them and abandoned them, unless they had a power of attorney for personal care.

The significance of that is absolutely profound, and I must say that it's extremely important for people to have in place a designated substitute they're comfortable with, because that implication is so serious. We've talked about the need for education. I know there are very few people

who have actually made that clear designation of substitute decision-maker. I don't think they realize the importance of that.

**Ms Quesnel:** They should.

**Mrs Caplan:** I agree, and that's an important message. I hope the government will do that kind of education so that people will understand the implications. At the very least, I think there is an obligation for them to include in this legislation the same requirement, perhaps not in the same detail. They have it in the Substitute Decisions Act, that before you are assessed for the purpose of capacity and guardianship you have to be told you're being assessed, you have to be told the finding of the assessment and of your right to appeal. There's an obligation under the Mental Health Act to do that and there's an obligation on the provincial guardian and trustee to do that.

Why is there not that same obligation on people who are professionals doing those kinds of evaluations for the purposes of treatment? The government hasn't addressed that and you've addressed it extremely well, and why that's so important, and I thank you for doing that.

The other point you've raised which we haven't really thought about—we've heard from a number of other groups—is that often vulnerable persons' pension cheques are controlled by their families, contrary to their wishes. I'm wondering, from your experience, how often that happens. Is that a rare occurrence or is it something that happens frequently?

**The Chair:** Thank you, Mrs Caplan. Mrs. Boyd.

**Mrs Boyd:** Bonnie, I wonder if you want to answer Mrs Caplan's question. Do you think it happens frequently?

**Ms Quesnel:** I think probably more than we'll ever know, really. The person, either seniors or disabled, may not even be aware of it.

**Mrs Boyd:** I want to thank you very much for your presentation. I must say you are a good example of how very capable people are of self-advocacy and of advocating on behalf of their friends. You make a good point, that we would be much better off if we were empowering disabled people to self-advocate and advocate on behalf of others than simply relegating them to social assistance.

You and I have talked before about this do-not-resuscitate problem.

**Ms Quesnel:** Yes.

**Mrs Boyd:** Other speakers have talked about similar concerns. I think it is a hidden sleeper in the legislation and one that people don't want to think about, because people want to believe that people will always act in the best interests. The problem is, as you point out, for many very caring people, they may think, as Mr Latimer did, that it is in the best interests to act in that way. We heard Father Lynch, I believe his name was, talk about the withdrawal of nourishment and hydration from people who may not be, but may be, in the end stages of life not being offered food any more. It's a similar kind of a thing.

You said you've had three different cases in your own small group where for issues that have nothing to do with a disability—

**Ms Quesnel:** Nothing.



**Mrs Boyd:** —people have been asked to put DNRs on their files.

**Ms Quesnel:** Nothing at all to do with their disability.

**Mrs Boyd:** That's very disturbing and I would urge the government to be really, really clear that this is one of the possible implications of people not knowing that they've been declared incapable and someone else being able to put something like that on a file with definitely life-threatening consequences.

**Ms Quesnel:** Most definitely.

**Mr Marchese:** The government members say or will tell you momentarily that you're such a great advocate and there are so many people like you that what we need to do is encourage people like you to advocate on behalf of people like yourself, and that if we have such great people, then we don't need a government to interfere, to provide advocacy. What is your response to that kind of question?

**Ms Quesnel:** I believe if ever we needed advocacy, now as much as ever before, it's needed now, because of a lot of impending cuts. People are being cut in hospitals, all over the place, and people have to have the feeling that what they say matters. It matters to themselves as a person, not as a third-class citizen. It's not fair.

**Mr Frank Klees (York-Mackenzie):** Thank you very much for your presentation. I want to commend the work that PUSH has done. As you say in your representation, perhaps "agencies, officials, paid caregivers and experts are self-serving," and I'm assuming you're talking about a bureaucratic type of advocate, that PUSH isn't like that.

**Ms Quesnel:** That's right.

**Mr Klees:** And that's what we're trying to encourage. I just want to get back to something that Ms Caplan made reference to, and I consider really very serious. I'll read to you from your presentation where you say, "PUSH members who recently sought medical support for correctable conditions, eg hernia, bronchitis and bowel obstruction, had been asked for this" do-not-resuscitate "designation while receiving treatment." Do you have personal knowledge of this actually taking place?

**Ms Quesnel:** Yes, sir, I do, and this happened here in London.

**Mr Klees:** I believe members of this committee share my very serious concern about this. I consider that to be a very serious breach of professional conduct, and I would like to follow this up with you so that we can get some details from you to ensure that this kind of activity is looked into, because certainly this is very serious.

**Ms Quesnel:** Yes, we know. There are a lot of people out there with disabilities who, even when they're asked to go to the hospital, are refusing to go because of this.

**Mr Klees:** We will follow that up with you. I think it's important for you to understand that certainly this government is not prepared to stand by and allow this kind of thing to happen in our community. We will be in touch with you. We ask you perhaps to prepare the details for us so that we can take some initiative on this with you.

**Ms Quesnel:** Okay.

**Mrs Boyd:** Mr Chair, on a point of order just with relation to that: I think the members ought to be aware that this has been asked for before and the individuals

concerned feel so vulnerable that they have been reluctant to come forward. I hope they will now, but I also hope that if they don't, then in a systemic way we can deal with this, because individual complaints are not the issue here. This is a systemic problem and we may end up being responsible for dealing with it in a systemic way.

**Mrs Helen Johns (Huron):** I just want to draw your attention to one your pages that starts with "Too Much Power": "A one-person appeal board is unreasonable. One person should not have all of the authority to judge capacity, appeal efforts or final outcomes." I just want to draw your attention to section 78, and I know you don't have your act here, but it basically says that there's an appeal mechanism if you're unhappy with what happens with the one-person board. I just wanted to draw to your attention that there is another mechanism that will allow for appeal process. So that's just not quite the way the act reads, okay?

**The Chair:** We thank you very much for attending this morning.

**Mrs Caplan:** On the point of order, Mr Chair: It might be helpful, given Mr Klees comments, if we asked the College of Physicians and Surgeons whether or not they would consider that professional misconduct, because they are a self-governing profession, and I think that would be helpful to your deliberations.

**Mr Klees:** Certainly, they would be brought into these discussions.

**Mrs Caplan:** The committee could request that or you could request that.

**Mr Klees:** Clearly.

**Mrs Caplan:** They are the ones who govern what's professional misconduct for doctors.

**The Chair:** Is there any concern about proceeding in that manner? We shall do so. We would appreciate your communicating, in some method, the specific instances so this committee can follow it up. We really do appreciate your attendance.

1040

JENNIFER WILCOX

**The Chair:** Jennifer Wilcox. We should have received Ms Wilcox's brief. You have 20 minutes. Would you please proceed.

**Ms Jennifer Wilcox:** I suppose I would consider myself a voluntary advocate if I look at the choices I have made in my life. Over the years, I have continued to find myself incensed with the unfair treatment of a fellow student or employee, a friend or acquaintance. And before I realize what I'm doing, I'm going through the process of what I now understand to be advocacy.

I am gravely concerned with the government's decision to repeal the Advocacy Act, not to mention my concerns with respect to the proposed Health Care Consent Act. I can only speak from personal experience, and although I could speak to the needs of varying types of individual persons, I will concentrate on my experiences which led to the formulation of most of my current opinions where advocacy and human rights violations are concerned. These experiences involved the care and treatment of my mother.



How did I come here today? What made me feel the need to address this committee and express my concerns about the plight of vulnerable people? No, I am not a health care professional, nor am I representing a special-interest group. I am simply the daughter of a dead woman, who during the last half of her life, slowly and agonizingly lost faith in the health care system.

A registered nurse by profession, my mother spent many years in her early life wanting to help people be well within the system that failed her. As an ill person, she was loyal, to her detriment, trusting, naïve, vulnerable. To her, doctors were gods who would never prescribe a treatment that was not necessary or be too busy or unethical to neglect the needs of their patients.

My mother, in my humble opinion, had the misfortune of putting her quality of life in the hands of a few less-than-compassionate physicians in the diseased phase of her life. My mother's family also trusted the health care system to provide her with the services to which they felt she was entitled.

As a teenager and young adult, I watched helplessly as my mother became increasingly dependent on prescription psychiatric drugs. My mother died of cancer, but when she died, she died a prescription drug addict. A resident oncologist at the Princess Margaret Hospital, where my mother died, felt the need to inform me that the lithium she took for years had irreparably damaged several of her internal organs, to which I replied, "Tell me something I don't already know."

I won't waste a lot of your time with details of my mother's death. Suffice it to say that my mother may have benefited from the services of an advocate, such as is described in the Advocacy Act. My mother's self-proclaimed familial guardians were, at best, people who loved her very much; at worst, they were people who were unaware and uninformed with regard to available services and treatments in existence for a person in her condition. Truly ignorant, either through blind faith or simple immaturity, my mother's relatives stood by and watched her life end. She had much to offer her community and was loved by everyone who had the privilege to know her, but her disease denied her the luxury of caring for herself.

Her disease crippled her to the point where she became vulnerable enough to be abused. An advocate may have been able to sufficiently educate my mother as to her rights and obligations with respect to her personal care. An advocate may have been able to enlighten my mother's family as to their rights and obligations with respect to her care. An advocate may have been able to act as a liaison between my mother, her family, the guardians when necessary, and the health care professionals tasked with the ominous job of identifying and curing my mother's disease.

As it happens, we'll never know if an advocate would have made any difference in the quality of my mother's life because she's no longer here. I will not, however, remain silent if I believe there are other people who are subjected to the pain, suffering and dysfunction which results from the witnessing of atrocities with respect to the maltreatment of vulnerable persons.

I can only imagine how I must have appeared to my mother's doctors. If their treatment of me was any indication, they perceived me to be an imbecilic obstacle to their cause. I could really have used the help of an advocate during my attempt to understand the system's treatment of my mother. As a naïve 16-year-old who had fooled herself into thinking she could help her mother, maybe I could have been spared the school of hard knocks if I'd run into an advocate.

My crash-course induction into the world of health care provision for the psychologically vulnerable was at times excruciating, to say the least. If some form of organized advocacy exists, perhaps other people can be spared the agony of either being abused or neglected or of witnessing such intolerable treatment.

My mother was fortunate to have many caring and compassionate health care providers over the years as well, and I am grateful to all of them for restoring my often dwindling faith in the health care system. My concern is with those service providers who are actually, I hope, a minority. Albeit questionable treatment may seem rarely to occur, experiencing it or witnessing it is detrimental to the wellbeing of all involved in such a situation.

Instead of being seen as someone who knew and understood my mother and her condition, I was treated as an annoyance that interfered with the doctors' mechanical dismantling and reworking of my mother's psyche. Due to my experiences in dealing with more than a few of my mother's doctors, it was very difficult not to generalize and assume that all psychiatrists were service providers who attempted to placate me by insulting my intelligence with their close-minded and condescending attitudes. Perhaps an advocate would have helped me to deal more effectively with these people who were tasked with the responsibility of helping my mother.

To her doctors, my mother appeared to be nothing more than a unidimensional, biochemical organism who cooperated as any good and compliant specimen would. If she wasn't seen as a whole person, then theoretically the violation of her rights was somehow more acceptable. If the thinking, feeling side of a person is neglected, then over time that side becomes non-existent. Apathy over personal care is perpetuated in vulnerable persons because they are often treated as if their personal care is unimportant or secondary to the care of less vulnerable people. For these demoralized and therefore vulnerable people effective advocacy is crucial.

One could argue that my mother was a cog in the psychiatric machine. One could also argue that much of the current medical systemic theories are close-minded and can at times actually perpetuate rather than cure disease. My mother existed in a state of learned helplessness. Family, friends and others who cared for her watched also helplessly and frustratedly as she slowly and painfully withered away. I recognize her responsibility for herself and I also recognize my responsibility as her daughter, as a family member involved in her care. But what of the responsibility of the doctors, the hospitals, the health care system, and the government, for that matter?

The breakdown in communication between and among health care providers, not to mention the often less than



perfect communication between health care providers, patients and their families, through little or no fault of their own, results in human rights violations. Health care personnel who are overworked, burned out and feeling unappreciated will eventually go beyond low morale mode to survival mode. The bottom line is this: Without progressive, proactive legislation and regulations, what ends up being compromised is the quality of life and even the life safety of patients receiving services provided within the health care system. Would any of us wish to be at the mercy of such a system?

Using the field of psychiatry as an example, the psychiatric political correctness where health care professionals are discouraged from expressing their concerns with respect to the care of patients; the arrogance of some narrow-minded doctors who insult the intelligence of patients and family members through their blatant disregard for the patient's and family's desire and need to help and be involved in the decision-making processes where the patient's recovery is concerned.

Falling through the cracks in the system—it's a catch-22, and it's a shame to me to think that there's a perceived need to defend oneself against a system created to help people. Vulnerable people feel incapable of defending their own rights for their own personal reasons, whether that's low self-esteem or low self-confidence as a result of poor life circumstances; anxiety or ignorance as to their rights; blind faith; detrimental loyalty to less than ethical health care professions. If elected officials within the provincial government create legislation in an ill-informed and ignorant manner, if politicians are ignorant to the plight of vulnerable persons, how can we expect to have quality legislation?

Legislation and regulations are minimal requirements. We, as a province, need to strive for the optimal care and treatment of all Ontarians. Such legislation should exist to promote respect and dignity for vulnerable persons, without violating their rights or compromising their care. The proposed Health Care Consent Act is comprised of violations just waiting to happen. Situations involving conflict of interest on the part of health care practitioners or guardians could become commonplace. How do you legislate subjectivity? Legislation is always open to interpretation. It can be interpreted or misinterpreted, used or abused. Care must be taken to ensure that legislation is not used as a tool against those it is intended to protect.

#### 1050

The proposed Health Care Consent Act is limiting. What about peripheral vulnerable persons who are not involved in the health care system, for example, children and parents versus the board of education in a problem situation? The Advocacy Act allowed for the representation and the regulation of that representation of all vulnerable persons. The Advocacy Act is a progressive, proactive attempt to prevent or at least lessen the likelihood of human rights violations.

On some level, animal rights issues get more recognition and support than the rights of vulnerable persons. Why do I think that is the case? In my humble opinion, seeing, hearing, acknowledging or recognizing the fact that human beings are being violated even still, at this

point in time, is frightening and overwhelming. It seems unthinkable. Perhaps people think that if they don't think about it, it'll go away. Maybe pretending that atrocities don't exist right here in Canada allows people to sleep more easily at night. Detachment, coldness and denial are all coping strategies to deal with our less than perfect world. Fear of difference, fear of pain, suffering and adversity can and often does lead to disgust, intolerance and discrimination against vulnerable persons and therefore the acceptance of human rights violations.

Being vulnerable has become stigmatized. Lip-service to the protection of vulnerable persons seems to have revived the old adage that only the strong should survive. If this is the case, has society progressed or regressed? What would be the point in participating in such a regressive and fair-weather society? It almost makes transient living seem palatable. No one owes anyone anything. Rely on no one but yourself and hopefully you can trust yourself, if not your community.

With respect to concerns regarding money issues, bureaucracy relating to the Consent to Treatment Act, the Substitute Decisions Act and the Advocacy Act, consider the pendulum analogy: Before these acts existed, the pendulum swung to the right and human rights were violated. Then over the last five to 10 years with the political correctness trend came a pendulum swing to the left, and again human rights were violated.

Can we learn anything from these extreme tendencies? Instead of waffling back and forth with constant fighting between and among political parties and special-interest groups, why not carefully and thoughtfully look at what has been created over the past 10 years? Before discarding the Advocacy Act, look at what is good about it.

Even capable people have vulnerable moments in their lives. Even well-meaning statutory guardians or personal powers of attorney, not to mention health care professionals, have moments of indecision. Where family members are in a position to make contentious, controversial, life-altering and even potentially life-threatening decisions, it is, as I hope you can imagine, a situation not uncomplicated by personal attachment and emotional involvement.

Advocacy, with or without the Advocacy Act in place, will continue because there are people in our communities who care enough to work on ensuring fair and just treatment of vulnerable persons. If there is no act, at the very least perhaps prescribed or recommended advocacy theories and practices in the form of regulations affiliated with another act could exist. Although advocacy may seem like common sense to a lot of us, good sense is not always common and ethical treatment of vulnerable persons is not always the rule.

These questions that I'm about to pose are directed at elected and government officials determined to repeal the Advocacy Act. These personal and rhetorical questions are meant simply to provoke thought, which may or may not lead to positive action in the best interests of vulnerable persons.

Have you ever had an adverse day in your life? Have you ever felt vulnerable to the point where you perceived that you were at the mercy of others? Have you ever been a party to despair, anguish, desperation or been



crippled with fear? Have you ever questioned the fibre of your very being? Have you ever known poverty?

Have you ever known, loved, cared for or been involved with a vulnerable person? If so, have you ever been a party to systemic abuses which resulted in rights violations of that vulnerable person or yourself? If not, can you empathize even enough to at the very least rework the proposed Health Care Consent Act? This proposal, as it currently exists, will not protect the rights of vulnerable persons.

This, as with every other social issue facing the province right now, is a money issue being masked so as not to appear to be a budgetary issue. What motivates people in power to alter otherwise necessary social services? Money. Power can be used or abused and greed can distort an otherwise well-meaning person's morality. Can we trust the politicians in the currently elected government to act in the best interests of Ontarians? I hope we can, but like more and more people in this province, I am becoming increasingly concerned about the social welfare of this province. What will be the point of having a balanced budget if there are no healthy people living in this province to celebrate that day?

The proposed Health Care Consent Act appears to be more protective of health care practitioners, guardians, attorneys and the health care system in general than the rights of vulnerable persons whose consent is in question. Statements to the effect that the Advocacy Act is expensive and bureaucratic are an example of the propaganda spouted by politically motivated individuals in an attempt to justify rash decisions to step back into the dark ages of questionable or non-existent social service provision for the citizens of Ontario.

There is as much a need for advocacy today as there ever was. Unless and until attitudes change and rights awareness is increased, the rights of vulnerable persons will continue to be violated. We are all at risk of becoming vulnerable persons. Advocacy is not just something that someone else needs. The day may come when you are vulnerable. Who will help you to know, understand and fight for your rights? An advocate, no doubt.

Thank you for allowing me the opportunity to address this committee and for your careful consideration of people's concerns with respect to advocacy and the rights of vulnerable persons.

**The Vice-Chair (Mr Ron Johnson):** Thank you, Ms Wilcox. We're going to move on now. We've got about one minute per caucus, that's all, for questions. We'll start with Mr Marchese.

**Mr Marchese:** I just want to thank you for your presentation because it's a strong case for advocacy for those who are vulnerable. You, yourself, said that you were not treated very well as an intelligent advocate of a parent in that situation, so even you were almost discarded in that situation.

You made a strong case for rights awareness. This proposal obviously, through Bill 19, takes away that rights awareness. In fact, it's not being promoted. What we did through the Advocacy Act is to promote awareness at a systemic level and to promote the fact that there are vulnerable people who need those protections. Rights advisers were there to give that assistance. If you take

that away, volunteers will not be able to do it. Even people like yourself weren't able to do it, and that's what this proposal through Bill 19 is taking away. I thank you for your personal case in this matter because that's what we need to hear.

**The Vice-Chair:** To the government side now; I've got Mr Clement and Mr Parker. You're probably only going to get one in.

**Mr Clement:** I'll try to do better, but I'll just focus in on and springboard off what Mr Marchese said. Thank you for your presentation.

If we decide to go the route of eliminating the Advocacy Commission, what would be the core of that service for you that you'd like to see still government involvement in? Would it be training and education of individuals who seek to advocate?

**Ms Wilcox:** That would be good. I think having some form of regulation with respect to advocacy would be a good thing. Training and education would be a good thing. Some form of government involvement would be a good thing. I don't really know the answer. I just think that what a lot of people spent a lot of time and energy and money working on to write, to create, I don't think should be thrown out. There were obviously enough people who thought it was important to work on for it to be created. It's beyond me how something like that could just be thrown out without any further consideration, because obviously there must have been a perceived need at some point in the last 10 years for there to be an Advocacy Act.

**Mr Clement:** There is a need, but it's how you deal with it.

**The Vice-Chair:** Mr Clement, sorry, we are going to have to move on now to the Liberal caucus. Mrs Caplan, you have one minute.

**Mrs Caplan:** Thank you very much. I listened and I must admit I related on a personal level. My father suffered from severe manic-depressive illness most of his adult life. One of the reasons that I'm so supportive of the Psychiatric Patient Advocate Office is that it was not in place to help him and there was no one to let him know what alternatives and choices there were, nor was he even aware that he could report as professional misconduct the fact that his psychiatrist would charge him for missed appointments when he was unable to cope, and of course there was no OHIP in those days. So I'm very aware of the vulnerability of people, not only with mental disability but also with other challenges in their lives that create a vulnerable situation for them.

**1100**

I guess the concern I have is that this legislation not only does away with any kind of coordination or training or education for the development of a system of advocacy but in fact the only people who are protected by the services of the Psychiatric Patient Advocate Office with this legislation really are those under the Mental Health Act in the provincial psych facilities. It's my hope that at least this legislation will be amended to increase the mandate of the PPAO and not allow administrators to appoint potentially untrained, uncertified—I'm just wondering if you want to comment on that.



**The Vice-Chair:** Thank you, Mrs Caplan. I'm sorry, we're out of time.

Ms Wilcox, I want to thank you on behalf of the committee for your presentation.

#### CANADIAN MENTAL HEALTH ASSOCIATION

**The Vice-Chair:** Next on the list is the Canadian Mental Health Association, London-Middlesex. That would be Judy-Marie Watson, as well as Alex Bezzina, the Canadian Mental Health Association, Waterloo regional branch. Good morning. You'll have 20 minutes for your presentation and you may want to leave some time for questions from the floor. You can begin any time.

**Ms Judy-Marie Watson:** I come before you today a representative of three diverse, conflicting stakeholders of the mental health system, having obtained, through my experience, what is sometimes perceived to be a unique perspective on mental health care. You see, I am a psychiatric consumer-survivor who, because of my recurring illness, still requires periodic access to professional medical services and the use of medication to reduce symptoms of depression that might otherwise keep me from fully participating in life.

I am also what is considered to be a family member, someone who lives with or experiences the mental illness of a loved one. Though fortunate to be part of a loving and close family unit, I have lost a niece and a nephew to suicide and am aware that others within my family are or have been in treatment for various affective disorders.

Third, I am employed by the Canadian Mental Health Association's London-Middlesex branch. I coordinate a community-based information and referral program where access to mental health services and supports is based on an individual's assessed needs and personally selected service and support goals. Through this work, I promote appropriate access to a significant component of the health care system that in recent years is forever changing, reforming, with each change and reform reflecting a need to save dollars instead of the ever-increasing need, demand and right of the individual for service and support of his or her choice.

The prevalence of mental illness is higher than that of cancer, heart disease and respiratory disease combined. For centuries, society dealt with mental illness by locking people away in asylums, an approach that insulated other citizens from the necessity of coping with sometimes bizarre behaviours. We are all aware that since the mid-1960s, long-term hospitalization has been largely discarded in favour of community-based treatment. The practice of deinstitutionalization was made possible by several factors, the most influential being development of psychotropic medications that assist in controlling, repressing and masking symptoms associated with mental illness. Implementation of patients' rights followed, leading to positive changes in legislation that allowed for the release of even more patients from hospitals and institutions, even keeping some who might be seen to benefit from treatment from ever being admitted.

With the imminent closure of even more hospital beds, a greater majority of people with a mental illness will reside in the community. Despite this, networks of

services and support agencies remain slow to develop due to bureaucratic and funding obstacles. In the Utopia we have planned towards through many years of mental health reform consultation, such a network of resources should actively participate in the provision of mental health services and social living skills, enabling a person with a mental illness to live in their community of choice.

Based on the premise that a person has a right not to be isolated from the community because they have a mental illness, community mental health's role has been to provide quality prevention, referral, treatment, rehabilitation and support services without relying on institutions or hospitals unless absolutely necessary. But in the midst of all this planning and these partnerships and continued amendments to legislative policy, many of us remain confused. Hospital beds are closing at a time when it is apparently becoming easier for professionals to provide treatment. We encourage the person with a mental illness to participate in their own care, then we take away their freedom to choose or reject that care dependent on the setting at which the care will take place.

I recall participating in public consultations and other forums over a period of several years that allowed for stakeholder input towards the implementation of the advocacy, consent and substitute decision legislation. Now the current changes in legislative policies, as covered in Bill 19, allow only these few hours of public commentary. Still, it is not simply any shortcomings in legislative implementation that are the only concerns bringing us here today. The bottom line is concern about people, vulnerable people who live in the province of Ontario, vulnerable people perhaps unable to manage for themselves due to disability being once again left few viable options. With Bill 19, the same psychiatric facilities responsible to and designated by the Minister of Health or Ministry of Health, institutions that once truly controlled the lives of people with mental illness, will now apparently provide them with rights advice and evaluate their capabilities regarding admission to a care facility and assess their capacity to consent to treatment. This is a major conflict of interest.

It is recognized that care providers, including physicians and case managers, frequently see themselves as advocates for or of the patient, but as the O'Sullivan commission recommended in April 1987, the essence of advocacy must clearly be distinguished from other service roles. Defining and understanding this difference is essential in order to move advocacy and rights advice from the realm of an abstract concept to the level of a viable, concrete service.

Our provincial government must remember that people who require mental health care also require advocacy assistance, as surely now as in the not-too-distant past when they had even less knowledge of their rights. This was previously true because a patient or former patient wielded no real power individually in relation to the organizations and institutions that controlled numerous aspects of their lives. Working towards a common goal, consumers, family members and community-based services learned that individual, isolated action was but a starting point to bring about the kind of changes that make it possible to live lives of dignity and wellbeing.



When people were encouraged to work alongside their peers, building strong organizations that they could control, designing strategy, taking action and improving the quality of their lives, the role of advocacy began to change in our communities. In recent years we started on the road to individual and collective empowerment. Bill 19 takes us all a step backward. It simply eliminates all references to advocacy and advocates. We ask that you correct this. To ensure the rights and autonomy of people in the province of Ontario, the following must be taken into consideration:

(1) Accountable only to the vulnerable person and not representative of the employer or caregiver, the concept of an independent Advocacy Commission is supported by a large sector of the population of Ontario.

(2) Advocacy and the provision of rights advice must be included in any legislation relating to consent and capacity.

(3) The provision of rights advice must be removed from the jurisdiction of the Minister of Health or Ministry of Health.

(4) Vulnerable persons must continue to be assisted to understand their rights in order to express their wishes and/or consent.

In order to further demonstrate these concerns, I ask that you think of people in Ontario with a severe mental illness like schizophrenia. One in 100 people have this illness; over 3,000 people in the city of London alone. People who are actively ill with schizophrenia often have delusions—hallucinations that have no objective source but are none the less real to them. They might believe others plot against them. They experience sudden changes in lifestyle and behaviour, and they suffer from extreme anxiety, panic, fright and confusion. These people are often highly intelligent and creative individuals, but society's tolerance for their symptoms and behaviour is quite limited.

There is nothing in Bill 19 that will make the opportunity or necessity for initial access to a health care facility an easier process for people experiencing severe schizophrenic episodes. We need to do more work in influencing society's attitude and amending the Mental Health Act to accomplish that task. However, because of Bill 19, once they are somehow presented for assessment and possible treatment, the strong possibility exists that:

(1) They will be left in the position of certainly having some rights but no way to ascertain what those rights are or how to exercise them.

(2) Capacity assessors are only required to inform about the purpose of a capacity assessment and consequences relating to findings of incapacity, but are not obligated to inform of the right to refuse the assessment.

(3) Should the person be unable to communicate due to the nature of a disability or a language barrier, the health care practitioner is required only to take "reasonable" steps to communicate or interpret prior to proceeding with treatment.

(4) They are subject to invasion of privacy as personal and clinical information about them may be disclosed without their knowledge or consent.

(5) They may be subjected to the use of restraints while in a care facility.

#### 1110

What of families? Bill 19 provides an amendment as to how "family" is defined, expanding it to include people related by blood, marriage or adoption. Yet despite this expanded definition, the contribution and participation of same-sex couples is completely ignored in Bill 19. Such expansion and omissions allow for the potential situation of a distant relative making health care decisions on behalf of an ill family member without knowledge of their preferred treatment wishes or previous treatment experiences. There is great potential for other decision-making abuses.

In the perfect world, we like to think that family members will always act in the best interests of loved ones. We also know that the world is not so perfect. Some family members should be the very last resort sought in decision-making matters. Additionally, the symptoms and behaviours of some mental illnesses are such that family ties have been broken or family contact restricted for very valid reasons.

Paradoxically, many family members are the primary caregivers, sometimes a landlord and often the only personal support for loved ones with a mental illness. While family members should not be expected to do the work of paid caregivers in the provision of services and supports, this has been the reality for many. The hardest question many a family can face is what to do about a relative who persistently rejects treatment. Aging parents fear for the future, as do adult siblings. With few exceptions, family support organizations are small and still building towards larger networks. As a result, the voice of families has not always been heard by government and policymakers, less often by health care professionals. The frustrating positions of these families require clarification of issues related to decision-making and consent.

While roles, rights and responsibilities of families may seem to have been elaborated on in Bill 19, there is still far too much room for conflict. Truly responsible, caring family members will not fear or object to accountability in decision-making matters. Put this obligation back into legislation by making accountability a major component of the Health Care Consent Act, so that those who choose to can continue to protect loved ones when they are most vulnerable.

I am not a policymaker, but I do believe in rights. I choose to work in an environment that supports advocacy, autonomy, choice and protection. We look to elected officials of this province to protect the rights of every citizen and to ensure that health care is available to those who require and consent to it freely. You are our voice in this matter. Please be sure that we are heard.

**Mr Alex Bezzina:** I thank you for this opportunity to address the standing committee on administration of justice regarding Bill 19. I come here today on behalf of the Canadian Mental Health Association, Waterloo regional branch, and the people we support in our community. I would like to begin by making some introductory comments regarding the lack of consultation regarding both the creation of Bill 19 and the legislative steps that are quickly being taken to pass it into law and achieve royal assent.



Bill 19 is indeed an extremely powerful piece of legislation in light of its far-reaching effects on the lives of so many citizens. Ostensibly, Bill 19 was created to minimize the role of government in people's lives and to put decision-making back into the hands of individuals and families. Moreover, Bill 19 has been created in response to the concern on the part of the medical community in the province over the previous legislation. Of significant importance is the fact that in the process of creating this new bill, vulnerable people have not been consulted in any meaningful way regarding the benefits that were extended to them by the previous legislation and how these were to be altered, even though they constitute the segment of our population which will experience the proposed changes most dramatically.

In light of the government's decision to take action regarding Bill 19 without corresponding planning and consultation with vulnerable people in our region, our branch of the Canadian Mental Health Association had planned to organize a community consultation evening with our local MPPs. The evening would have provided an interactive forum for community members to come together to understand and discuss the implications of the legislation. The evening did not occur due to the speed with which this consultation process is advancing and our difficulty in arranging such a forum in a short time. It is indeed unfortunate that such forums were not initiated by this committee for the purposes of meaningful grass-roots consultation throughout the province.

I would like to utilize the remainder of our allotted time to speak to the issue of capacity in general and more specifically to section 22 of the Health Care Consent Act, 1995.

The Health Care Consent Act introduces legislation that addresses the issue of consent in two areas of people's lives that have heretofore not been subject to legislation; namely, admission to care facilities and personal care plans. In doing so, the act also provides for the possibility of incapacity to consent and consequent legal intervention in these two areas of personal decision-making.

The act makes possible the legally enforceable intervention by other parties into personal care matters such as how a person is to dress or wash, what she or he is to eat or drink, and where she or he may live or even venture. These implications would seem to belie the government's stated intention in revising the legislation at the outset, specifically the reduction of the government's role in the lives of citizens. In fact, the Health Care Consent Act does the opposite.

I will now direct my comments to section 22 of the Health Care Consent Act. Subsection 22(1) allows for the substitute decision-maker to consent on behalf of a person deemed mentally incapable to the admission of that person to a hospital or psychiatric facility for the purposes of treatment to which the substitute decision-maker has also consented. However, subsection (2) further specifies that should the admission in question be to a psychiatric facility and should the person deemed incapable object to that admission, then the consent can only be provided by either a court-appointed guardian or

an attorney for personal care, but only if that attorney has been authorized to use due force.

Section 22, when considered in combination with other proposed legislative changes as well as social factors, can lead to potential abuse against the rights of citizens; namely, the long-term, enforced and unnecessary detention of people in psychiatric facilities. Some of the proposed legislative changes that would potentially impact in this manner are as follows:

(1) The proposed deletion of subsections 46(10) to (12) from the Substitute Decisions Act and amendments to section 49, which would remove the requirement of an explanation to the affected person of a decision made by an attorney for personal care, or their right to object to such a decision.

(2) Changes made to section 50 of the Substitute Decisions Act no longer allow for a person to revoke the power of attorney and the addition of paragraph 50(2)4 would force the person to waive any rights to review the findings of incapacity. Meanwhile, the person, powerless to make changes, would continue to be forcibly treated and detained.

(3) Changes to section 9 of the former Consent to Treatment Act and the new section 16 of the Health Care Consent Act no longer require rights advice to someone who has been found incapable of consenting to treatment.

Given these proposed legislative revisions, there is great potential for people being treated against their wills, for long periods of time, and in facilities that not only alienate people from their communities and their lives, but which are also known to harbour other forms of abuse against those who are in their care.

Treatment plans have always had the potential for longer-lasting benefits when they are carried out with the full understanding and cooperation of the person, when they are carried out in non-intrusive environments, among familiar faces and things, and when the plans are supported by family members, friends and significant others in the natural environment. Consider further that the treatment in a psychiatric facility is usually comprised of receiving pills three or four times a day, seeing a doctor once every day or so, and spending the rest of one's time languishing in an unnatural setting with locked doors, strange rules and few privileges. Forced confinement to a psychiatric facility for the purposes of treatment could rarely be seen to be in the person's best interests. The very nature of forced confinement and treatment has the possibility of making a person even more resistant to treatment.

An additional concern exists: There is no legislative provision that would prevent the possible conflict of interest that would result if an employee of a health care facility were the person who performed the assessment of capacity for the purposes of treatment within that care facility. The possibility exists that employees of psychiatric facilities could find a person incapable of consent and could in turn provide information to substitute decision-makers in such a manner as to influence the decision to consent to treatment within the psychiatric facility. With the current trend to downsize psychiatric hospitals, the possibility that employees of these facilities may want to substantiate the need to keep hospital beds open and the



concurrent deployment of hospital personnel into the community as members of mobile treatment teams, such conflicts of interest could potentially arise.

These sorts of conflicts of interest have already been reported in other jurisdictions, along with the criminal acts of abuse that have accompanied them. An extreme case was reported in Florida. A particular segment of a news program on ABC-TV entitled 20/20, which aired in January 1996, reported the following: Psychiatric hospital staff who were deployed into the community were shown to be entering homes of elderly people without invitation. After a brief review of the home, the staff were declaring these people incompetent. Staff then sought legal recourse to forcibly remove these elderly persons to a psychiatric facility for the purposes of treatment. These people were kept in hospital, often without the awareness of their rights or the wherewithal to contest the declaration of incapacity. They were most often released once friends or family sought assistance to have them discharged, but the process took weeks. Other criminal forms of abuse were often visited upon these people. The news reports showed evidence that would suggest these admissions were done in order for a hospital to bill Medicare, to assist these hospitals that were not as financially solvent as would have been desirable.

In light of all this, we would make the following recommendations to the standing committee regarding Bill 19:

That an amendment be made to Bill 19 that would include a conflict-of-interest clause for assessors/evaluators of capacity vis-à-vis treatment etc.

That a clause be inserted in section 22 of the Health Care Consent Act that would require a weekly review to determine whether the required treatment that was consented to by the decision-maker could be offered in a less intrusive manner; for example, in the person's home.

That section 16 of the Health Care Consent Act be amended to include a requirement that rights advice be provided to any person who has been found incapable, and that other sections be amended in like manner with respect to consent to admission to care facilities and personal care plans.

That subsections 46(10) to (12) and section 49 of the Substitute Decisions Act be amended to require independent notification to the grantor of any decision to grant the power of attorney for personal care, and further explanation regarding the right to contest.

That the new paragraph 50(2)4 of the Substitute Decisions Act be deleted in order to allow a person to apply to the Consent and Capacity Board for a review of the finding of incapacity.

**The Chair:** I want to thank both of you for your presentation. Your timing was impeccable. There will be no time left for questions, and I want to thank you on behalf of the committee.

*The committee recessed from 1122 to 1320.*

#### HUGUETTE OUELLETTE-TRIES

**The Chair:** Our first submission will be by Ms Ouellette-Tries. You have 20 minutes, if you would proceed.

**Ms Huguette Ouellette-Tries:** Thank you, Mr Chairman, and the committee for allowing me to be part of the hearings on Bill 19. Since I am appearing as an individual, I have taken the liberty of presenting my credentials which attest to my extensive involvement and experience related to disability issues.

I would like to refer to the third item on my biography because I just learned yesterday in Ottawa that the coordinator of the Carleton Disability Awareness Centre was to make a presentation. Of all the activist projects I have undertaken in the past, this is probably one of the most gratifying, and one of the instances where one has been able to measure the success of one's initiatives.

My presentation will address the urgent need to establish a new system of advocacy as an alternative to the repealed Advocacy Act in order to meet the immediate needs of the most vulnerable persons. As well, arguments will be presented regarding the amended Consent to Treatment Act of 1992 and the new Health Care Consent Act.

My perception of vulnerable individuals conjures up images of the poor; the homeless; victims of abuse; abandoned, frail, aged citizens; stigmatized persons with disabilities. They are the silent, forgotten or rejected segment of society. They are being denied their basic civil and legal rights and have no recourse to or resources to help them claim their entitlement to freedom of access to services. It was in the spirit of helping vulnerable persons help themselves in claiming ownership of their life that the Advocacy Commission was established. Now, with the innumerable social crises surrounding us, advocacy for the voiceless population is needed more than ever.

The more complacent segment of society is quickly becoming sensitized to the sight of the homeless and death on the streets. "It is their own fault, their choice. Why should we concern ourselves? We have our own problems to deal with and we manage on our own," say the critics.

To those who decry the fact that too much fuss is made over the homeless since so many refuse help, I want to say that armchair critics should be urged to educate themselves on the sources of their misgivings of people refusing help, for most individuals who risk dying on the streets rather than seeking shelter have lost all trust in their fellow humans. Living on the streets is their only way of clinging to their freedom and, in their way of thinking, of retaining their dignity.

This illustrates the need for a renewed Advocacy Commission, which would include people who "have walked the walk." They might best be able to reach out to vulnerable individuals and help them regain a sense of self-worth and trust in society.

"Poverty is the cause of the defects of democracy," wrote Aristotle in his treatise on democracy. This tenet is still valid in the eyes of the guru and social conscience of 20th-century economists and champion of democracy, John Kenneth Galbraith. In a recent TV feature interview, he stated that "the problem with today's free-market economy is that it lacks compassion and erodes democracy."

As citizens of a society which prides itself in being one of the most democratic and caring in the world, we



should reflect on these thoughts. There are many poor and vulnerable persons among us and they are not disposable. They have basic rights which, too often, are not being respected. For this silent majority we need advocacy more than ever.

In his statement at the opening of these consultations, the Attorney General claimed that the Advocacy Act was intrusive upon the rights of individuals and the members of their families. The notion that everyone has a family or has the ability to ascertain one's rights is a utopian vision of an ideal-type society. The reality is that the majority of vulnerable persons does not have the support of a family and does not have the skills or resources to claim their rights.

It is reported that the government has suggested replacing the Advocacy Act with "a new and better system to support the interests of vulnerable people." Members of the former Advocacy Commission have already submitted a proposal outlining the possible restructuring of the commission under a non-profit corporation model. It is stated that the government is considering the proposal with the stipulation that the corporation's board members be appointed by the government.

The stakeholders should have reservations about this provision. Not only does it contradict the Ontario government's repeated claim that it is aiming at giving more power to the people, but this arrangement would also create conflicts of interest. Too often in the past, I have seen the most creative and efficient leaders of the disability community being pulled out of the activist loop to take on government positions. Inadvertently, they had to adopt the role of bureaucrat in order to secure their job. One cannot serve two masters.

The same applies to rights advisers who will be appointed by the psychiatric facilities or the ministry, as stipulated under the new act. This is also a situation of conflicts of interest, because it is not wise to challenge the practices of the employer, who hands out the paycheck.

Hence, in my view, objective representation should be sought from the communities in the selection and appointment of persons to any functions relating to advocacy for vulnerable persons.

The new Health Care Consent Act, amendments to the Substitute Decisions Act, 1992, and the Consent to Treatment Act, 1992: Under capacity to consent, the new Health Care Consent Act, 1995, states that person can be declared incapable by a "health practitioner," and among the individuals and groups listed in the act figures the College of Medical Radiation Technologists of Ontario, my former professional organization. I can attest to the fact that the training of medical technologist focuses on the theoretical and technological aspects of clinical diagnoses; it does not include the assessment of mental capacity.

As there appears to be no reference in the new act to establishing standards on assessment of capacity, one would be justified in foreseeing abuse of power by some health practitioners. Moreover, it is quite predictable that improper diagnoses of incapability will increase dramatically. It will be more expeditious to maintain the stream-

lining process of service delivery. In addition, recipients claiming their rights are an extreme irritant to overworked practitioners. As a result, this often leads to the "non-compliant" or even "irrational" label being recorded on the individual's records. This alone could lead to a presumption of mental incapability. Regardless or because of the individual's level of awareness, one feels totally helpless. I know; I've been there. These labels might well be recorded permanently with the introduction of the health smart card. The concept, just unveiled by the Minister of Health, is alarming.

This situation is doubly critical for persons with disabilities. It is well documented that in this instance practitioners focus primarily on the disability, which is frequently unrelated to the illness for which the individual is seeking treatment. This is even more threatening for persons who have problems communicating verbally or for individuals who have experienced any form of psychiatric problems in the past, even when treated successfully. I presume this would also appear on the smart card eventually.

It is evident why rights advisers or advocates are perceived as intrusive, as they disrupt streamlining. Furthermore, there is still a deep-rooted public belief that all health practitioners are infallible. Hence, it is far less disruptive to convince trusting family members of an individual's incapability than having an outsider intervene.

I would also like to address the electric shock therapy as aversive conditioning. Subsection 43(5) of the amendments to the Substitute Decisions Act, 1992, stipulates under subsection (12), "The guardian shall not use electric shock as aversive conditioning and shall not give consent on the person's behalf to the use of electric shock unless the consent is given...in accordance with the Health Care Consent Act, 1995." This is a substitution to subsection 66(12) of the 1992 act, which clearly prohibits a guardian from giving consent to electric shock therapy as aversive conditioning on another person's behalf.

### 1330

However, the new Health Care Consent Act makes no reference to electric shock as aversive conditioning, but it could be implied in section 21 of schedule A as an ancillary treatment. This section gives authority to an individual to consent on another person's behalf to treatment, including ancillary treatment, "even if the incapable person is capable with respect to the necessary and ancillary treatment." This would be consistent also with item 13 of the explanatory notes, which states that "a substitute decision-maker is no longer prohibited from consenting on the incapable person's behalf to a treatment involving the use of electric shock as aversive conditioning."

Furthermore, section 21 contravenes section 15 of the new act, which states that if a person returns to capacity, and I quote, "with respect to treatment...the person's own decision...governs."

Such calculated manipulation of the act is deceitful and unacceptable. Animal rights activists are more successful at protecting the rights of animals than we, as a civilized society, do for our own kind.

The same also applies to all other forms of behaviour modification as aversive conditioning, which is also



inhumane, abusive and judged to be ineffective by most competent therapists. A compelling case in point was presented by the CBC 5th Estate on January 2, 1996. The report exposed a behaviour modification treatment program using aversive conditioning and its director's practices in treating persons with head injuries. The staff of the facilities was trained to use painful physical force and abusive language to subdue the patients. "It was nothing less than torture," declared an emotional former male staff.

The treatment facilities provided by Chedoke-McMaster Hospitals were located in an isolated area. The director's professional qualifications were never questioned by the hospital's administration. Following repeated complaints by staff members to the administration and the Ontario Ministry of Health, the director resigned, but that did not prevent him from opening a private group home for individuals with head injuries. It has been confirmed that the same techniques of aversive conditioning were being used on the residents. Following the 5th Estate investigation, the director sold the home and appears to have vanished from sight.

Another dismal facet to this project is the fact that Premier Harris gave thumbs up to this initiative. It likely fitted into the plans of having all persons with head injuries treated in Ontario rather than sending them to the US. This also points to the government's aim of supporting privately operated rehabilitation treatment centres rather than providing funding for the existing certified public facilities.

In contrast, there are a few public centres in southern Ontario where persons with head injuries are being treated successfully, but these facilities are struggling to remain in existence. Dedicated staff members, along with the clinical director and family members, use a team approach to providing treatment specific to each individual's injury. I witnessed a humane, holistic and effective model to treatment for head injuries while being a patient at St Vincent Hospital in Ottawa. Although I was there for clinical rehabilitation following orthopaedic surgeries, I had the good fortune of observing the dynamics of the head injury recovery program, as I was assigned to the same physiotherapy facilities. Individual progress was reviewed by the team on a weekly basis. Patients were allowed and encouraged to test their limitations and were not ridiculed or chastised for failures. It was okay to try again, to express frustration and to cry. In some instances, patients and staff would cry together, in the same way that joyous moments were shared. There was no isolation room, no punitive treatment, no physical force used.

London also has a head-injury ward at Parkwood Hospital. There is no doubt in my mind that the same approach to treatment is being followed, for I am aware of the model reputation of its director; she was a senior resident at St Vincent Hospital during the course of my rehab treatment there.

The purpose in describing this approach to treatment has been to demonstrate that behaviour modification through aversive conditioning is not considered by most competent health practitioners as a humane, effective

form of treatment. Proponents of Bill 19 should be concerned about preventing abuse in aversive conditioning of all patients or residents of treatment facilities. There are alternatives. In my opinion, behaviour modification through aversive conditioning should be banned.

In conclusion, I would like to convey a personal message to Mr Harris. Like you, sir, I ate baloney sandwiches in my youth. In addition, I was 12 years old when I first tasted a banana. I wore hand-me-downs till I went to high school. My mother taught three generations in a one-room schoolhouse while raising 10 children. My father built our house, which still stands on the family homestead in a rural, have-not corner of New Brunswick. He served as a municipal council member for nearly 40 years. He championed social justice and advocated for the numerous poor and vulnerable members of our community. He ensured that funding was made available to shelter and feed the homeless, that nursing homes for the aged provided adequate care and that the destitute had access to essential medical care.

My parents believed in free enterprise. We lived modestly, but we were better off than many others. Whatever they gained was attained through hard work, but never, never was this achieved through exploitation or oppression of disfranchised or vulnerable people.

"This was a different era, a different world," will say the demagogues. "We must face up to the realities of global changes in order to secure a prosperous future."

But over the centuries and through many civilizations, history has shown that social justice and fair treatment of disadvantaged populations are the underpinning of thriving democratic societies.

**The Chair:** Thank you. We only have 30 seconds per caucus.

**Mrs Caplan:** Thank you very much for an excellent presentation. I think you've sent a very strong and powerful message to the government, and I hope they've heard you; I doubt it, but I hope they have.

**Mrs Boyd:** Thank you for coming today—I really appreciate the effort it takes—and for sharing your strong belief in advocacy. I know there often haven't been advocates around a lot of the issues that you and others like you have faced, and that's why we too want to see the Advocacy Commission or something that will stand in its stead established in Ontario, so we thank you for your support.

**Mr Clement:** Thank you very much for your presentation. I just wanted to refer to your comments about a possible replacement to the Advocacy Commission. I understand that you had conversations with Mr Reville, and there might have been a misunderstanding that had occurred, not through anybody's fault, but just a miscommunication. I want to let you know that the government hasn't got plans at this point to appoint, by themselves, commissioners to a new commission or what not. We're looking at Mr Reville's proposal and taking in the input from the communities affected. Certainly we'll have something a bit later, but we haven't decided absolutely that there are going to be government appointments.

**The Chair:** Thank you, Ms Ouellette-Tries, for your presentation.



1340

INDEPENDENT LIVING CENTRE,  
LONDON AND AREA

**The Chair:** Our next submission is from the Independent Living Centre, London and Area, Steve Balcom.

**Mr Steve Balcom:** Good afternoon. I think I've been here before.

**The Chair:** You should be experienced, then. Excellent.

**Mr Balcom:** One might think so. Just bear with me a sec. I move a little slowly, but I get there.

Thank you for allowing me to speak to you this afternoon. Before I begin reading my submission, I want to make a point of requesting the current status of long-term-care reform, especially in light of Bill 26 and the bill now being considered, Bill 19. We, as long-time advocates—and anyone who is vulnerable, for that matter, whom I'm representing—have a right to know, clearly stated, which areas of long-term-care reform are in, which ones are definitely out and which ones are being considered for repeal. To this point, we really haven't gotten a clear message from this current government. This is not to say we don't have a fairly good rapport with our local area office for long-term care; we have enjoyed in the past and still have a fairly good local rapport. What we need, as advocates, at this point in time are written reassurances about the exact status of long-term-care reform, especially in light of Bill 26 and this pending—I hesitate to call it—bill that we're facing at the moment. I will now proceed.

**The Chair:** Is there anybody who can assist us with that? Possibly after, so we don't take up your time. We'll try to get the staff to help you afterwards.

**Mr Balcom:** That's fine. The Independent Living Centre, London and Area, is a non-profit organization comprised of people with all types of disabilities. The obligation of each member is to help and support each other. This is done through provision of peer-mentor programs, education and resource materials, as well as program and policy design and evaluation services. Our commitment is to assist people with disabilities to live, contribute and grow in their own community.

It is our belief that eliminating independent rights advisers; assuming that paid caregivers and families always act in the best interests of people with disabilities; increasing the ease by which someone can gain control of a vulnerable person's life; and ignoring aspects of autonomy in any area—these four actions—will ensure that individuals with disabilities are being left unprotected and their vulnerability increased. In Ontario, criminals have greater access to rights advice and advocates than we do, especially in light of what's being considered in this current bill.

It is our perception that Bill 19 reflects government's unwillingness to accept responsibility for vulnerable individuals. This naïve posture of non-awareness creates an artificial barrier to understanding what our real experiences are. You do not comprehend the pressures, prejudice, denial and ignoring of our rights and opinions, the presumption of knowing better and abuse we have experienced at the hands of professionals, agencies, health

care systems and families throughout our lifetime. I'm thinking back specifically to the presentation earlier this morning of the individual who was talking about their mother. That really hit home with me. It was valid also because they were able-bodied, so their comments had more merit than mine, as a person with a disability, because I'm a special-interest group. I just thought I'd throw that in.

Your world does not allow us the economic and social experience of adulthood and personhood that each of you have experienced. Our glass ceiling was built at birth; this bill ensures it will not be moved.

We have heard the rhetoric about what Bill 19 will achieve. However, the reality is that the outcome will mean that vulnerable people will not have a voice, it increases the likelihood that we will lose our rights to make any decisions, and it increases the likelihood of abuse. This occurs because Bill 19 ignores the need for vulnerable people to know their rights and express their wishes. It ignores the need for systematic advocates to promote the rights of vulnerable people and to identify risk situations and remedy them. Presumptions of independence are not an inherent part of Bill 19.

Contrary to popular myth, ignorance is not bliss. If one's capacity is being challenged it seems a courtesy to advise them of it. If they are fortunate, they will have someone to help them. If they are not fortunate, they will have to rely upon the fluff available to them through Bill 19. There's nothing substantive in this act that will prove a benefit to those who are truly vulnerable. We want independent advocates available when we need them and we want to know where to find them. This presumption that a person will know that they even have rights is not necessarily true. We want advocates who will not barter our wellbeing for political favour, financial gain, or convenience.

The definition of "family" is just too expansive. This is merely to illustrate a point: If Tammy Homolka had been disabled, is it possible that Paul Bernardo could have been described as a family member advocate? It's a little scary. Did Tracey Latimer truly benefit by having a family member make decisions on her behalf? We think not. We think this is one of the faultiest assumptions in this legislation known as Bill 19.

I've heard this next statement echoed time and again throughout the presentations: Paid caregivers cannot become the appointed guardians of vulnerable people. This opens the door to the potential of massive abuse of vulnerable people. Unnecessary testing, aversion therapy—for example, cattle prods et al—use of restraints, invasive medical procedures, experimental methods and more befall those who rely upon the goodwill of paid caregivers.

This cannot be the intent of Bill 19. Perpetuating the misery of the vulnerable is not a positive change; it is regressive. It is victimization of vulnerable people at its worst. No responsible legislator would conceive of such a diabolical plot to destroy the meagre allotments of autonomy remaining to people with disabilities.

I know these are strong words, but you've got to realize our individual and collective experience. Those of

us who have lived in institutions—and I'm speaking from personal experience—have experienced this first hand. It is clear to me that this concept does not come to you from any person with a disability. We know better.

Bill 19 reduces the accountability of guardians. There will no longer be a necessity to file regular financial reports. Even if the vulnerable person wants to know their financial standing, it would require an expensive and convoluted procedure to obtain it. Again, it's an example of the fact there may be a mechanism there, but the reality of our financial dependence says that we won't likely access that avenue. It costs money, and that person's money is controlled by the guardian in question. It seems to me like a conflict of interest. Is a corrupt guardian going to authorize this process? I think not.

**1350**

Bill 19 removes the requirement that a guardian of a person may only use restraints or monitoring devices when it is included in the guardianship plan. This means that guardians will now be free to use restraints and monitoring devices without any accountability or even the limited oversight provided by having to outline the intention to use restraints. There are no limits. This amendment removes even the most basic protection by no longer requiring the guardian to inform the court that they intend to use restraints in their capacity as guardian and the circumstances under which they are being used. Even those responsible for incarcerated criminals must be accountable for confinements and disciplinary measures.

Previous legislation allowed vulnerable people to retain decision-making to the greatest extent possible, recognizing that capacity may vary on the type of decision to be made or the person's condition on a particular day. I'm thinking specifically of degenerative disabilities, as an example.

Bill 19 shows no respect for this concept and eliminates these requirements, undercuts the autonomy of vulnerable people and will lead to abuse. Not potentially. Trust me: It will lead to abuse. This is another example that the authors of this bill have no respect for or an experiential reference point regarding disabilities. Would people with developmental disabilities agree to this? Would people with MS offer this as a suggestion? I think not.

Bill 19 would permit a person to be admitted to a care facility without their consent or a substitute's consent in a crisis. The question is, whose crisis is it, anyway? Could it be a monetary or staffing crisis of the service provider which the individual will be blamed for? Will the lack of personal consent be ignored to serve care managers better?

In conclusion, with Bill 19 we have lost independent advocacy; we have lost rights advice; we have lost accountability to the person with the disability. We who had nothing to lose have lost it all.

The most vulnerable in society need the government to take responsible action on their behalf. That responsible action requires correct information. We will be available to help you amend or replace Bill 19. Tracey Latimer, and others whom we mourn, will not. We speak for them.

**The Chair:** Thank you, Mr Balcom. We have about two minutes each.

**Mr Marchese:** Thank you, Mr Balcom, for your presentation. I have to say to you that there are many people who agree with many of the things you have said, and the last point, on the issue of crisis and who defines a crisis and how people are left vulnerable in that situation because there's no definition of it, worries a lot of people. Your concern about the lack of rights advice has been stated by most of the deputants who have come here today. Your comment on there no longer being a necessity to file a regular financial report is something that concerns people. "Paid caregivers cannot become the appointed guardians of vulnerable people. This opens the door for abuse," is something most people have spoken about.

As a last comment, if there is this time, this government thinks that advocacy can be provided by possibly volunteers—certainly not government, possibly volunteers. Maybe they can be trained. We don't know who they are. But do you think there can be such a system out there that could help people like yourself or people in these vulnerable situations?

**Mr Balcom:** Speaking from years of experience in this area, of not just myself but many other colleagues, there's a naïve presumption by this current government that the voluntary sector is going to become the fourth level of safety net. We're not that naïve. There aren't enough of us who have made it a point of training ourselves, basically, of getting the training we need. There are not enough volunteers available, and there sure as heck haven't been from this government any offers of giving grants to allow us to increase staffing to allow advocates to be hired and trained and anything else. The naïve notion that it's just going to automatically be picked up by the voluntary sector is more than naïve. In my estimation, they're neglecting their responsibility as a government.

**Mr Parker:** Thank you for your submissions. You've spoken quite eloquently. There are two points I want to respond to and help you out. On the fourth page of your submission—

**Mr Balcom:** Give me a minute to go back there.

**Mr Parker:** —you have suggested that if a "vulnerable person wants to know their financial standing, it would require an expensive and convoluted procedure to obtain" access to the financial records. I just wanted to point out to you that on page 32 of the bill—that's clause 60(c.2)—there's regulation-making authority in there that would allow further detail to be added to the rules as to how records are to be kept and how they are to be disclosed. Your comments today will be very helpful to the draftsmen when establishing the regulations under this provision.

Another point that you made, and I want to respond to this one, is that in your submission, "Guardians will now be free to use restraints and monitoring devices without any accountability" or without limitation. Again, I just want to point out that there are limits. There are limits under the present legislation, and those limits will remain under our legislation. They are being retained, and I'm referring there to clause 66(10)(a) under the existing legislation, which we are retaining in our bill.

**Mr Balcom:** I thank you for the clarification, but it begs the question I must ask at this point: Why is it only when this government is pressed for an answer—and



basically I'm using a euphemism here. Why is it when you are backed into a corner and an answer demanded, it is then that an answer is forthcoming? I am not only speaking necessarily to you specifically at this point in time, and I appreciate the clarification, but why must the onus be on us to basically browbeat you into submission to get a response?

**Mr Parker:** We—

**The Chair:** Thank you, Mr Parker. Your time is up.

**Mr Ramsay:** Steve, thank you very much for your presentation. What I wanted to ask you is, were you consulted while Bill 19 was being drafted?

**Mr Balcom:** No.

**Mr Ramsay:** Then I would hope that the government members will keep in mind some of the suggestions you've made here. You make a very powerful statement on page 1 that we also heard this morning, that I agree with, when you say, "In Ontario, criminals will have greater access to rights advice and advocates than do we." You're right, and it's something that we in the official opposition are pushing, to make sure that you are advised of your rights. I think that's very important.

I have a question for you. You say, "Previous legislation allowed vulnerable people to retain decision-making to the greatest extent possible, recognizing that capacity may vary on the type of decision to be made or the person's condition on a particular day." Can you tell me, or could you find out for me later on, exactly where that is, because I'd like to look at that.

**Mr Balcom:** I'll find it out for you.

**Mr Ramsay:** Because I think you're right: That flexibility needs to be there.

**Mr Balcom:** I will definitely look into it later, but the one thing that comes to mind, and it comes back again to the Advocacy Act itself, one of the provisions under the act was that it not only speak to rights advice specifically but also impart information to vulnerable people—okay?—train advocates and make them aware of their rights. I think that partially speaks to your question in terms of that was definitely part of that piece of legislation. As to the specifics otherwise, I will gladly go back and figure out specifically where that came from.

1400

**Mrs Caplan:** Time for one short question?

**The Chair:** No, time is up. Mr Balcom, I'd like to thank you for your presentation and sharing your concerns with us.

**Mr Balcom:** Thanks for your time.

**The Chair:** Is there someone present from the Western Ontario Therapeutic Community Hostel, one Bill Cline? If there is not, we will proceed to the one slated at 2:20, the Neighbourhood Legal Services - London, Bruce Wright. You'll be next then, if you would.

**Mrs Johns:** Mr Chairman, I'm going to answer some questions on long-term care for him too. Okay?

**The Chair:** Sure.

**Mrs Caplan:** I don't mind if you do that on the record while the other person is coming forward, if we have a couple of minutes.

**Mrs Johns:** Okay. Is that what you want? I'm just going to talk to you about long-term care while you're moving back. Is that okay with you?

Long-term care has been identified as one of the areas that's of key importance to this government. The minister, within the last two or three weeks, has announced a new concept which is called the community care access centres. Basically what we're saying with that centre is that the people who have provided services in the past will still provide services in the community, that we won't be changing the services. However, there will be a different process involved in it.

We're talking about a nine-month time frame that we will be looking at implementing the new community care process. But the services that have been available in the past, for example, personal care support services or home care, will still be available in the future and will be there for the needs that the community represents. The community will have more input into what kind of services are needed and required, but we believe it will better meet the needs of the community as we proceed forward. So you're talking about a nine-month time frame here. I'd be happy to send you any information that could help you on that.

**Mr Balcom:** I am partially aware of what's pending. What we would need to know is, every time—

**The Chair:** Mr Wright.

**Mr Balcom:** What is pending and what is being considered to be repealed in the context of these two—

**Mrs Johns:** In the act itself?

**Mr Balcom:** The standing of the act itself in terms of what's in, what's out.

**Mrs Johns:** Okay.

**The Chair:** Mrs Johns, perhaps you could accompany Mr Balcom and give him the information he requires, if possible.

## NEIGHBOURHOOD LEGAL SERVICES LONDON

**The Chair:** Welcome, Mr Wright. You have 20 minutes. Please proceed.

**Mr Bruce Wright:** I represent Neighbourhood Legal Services. It's a general service community legal clinic. We do, as I say, general service, so among our clients are what might be classed as vulnerable persons, basically outside institutions, not in institutions, with problems with social assistance, problems with their landlord, that sort of thing.

Actually, I think I'm following up on what Mr Balcom has just spoken about. This is a very modest proposal that I'm placing in front of you, and it follows up on one of the key concerns, I guess, of Mr Balcom. One of the hats he wears is that he is a director of our community clinic.

Clearly, one of the concerns is the need for some kind of communication to the person who is or may be mentally incapable of making a decision or giving consent or refusing consent. The suggestion that I make here is, and I just draft it as a suggestion, you might make a requirement in the act, by very few changes—and I'm talking about the HCCA in particular—to make a requirement that the person be advised of a decision that has been made, a decision as to incapacity or a decision about a substitute decision-maker, having to do with treatment or admission to a care facility or to a personal

assistance plan. If you look through that, I have just mentioned the sections or the parts of the HCCA which cover them.

Under capacity, I've suggested just about where in the legislation a requirement for notice be given to the person who, in the first example with respect to capacity, has been declared incapable with respect to a treatment. I suggest that it should be a written notice. I think that would make a kind of standardized requirement so it wouldn't depend on the time or the presence of a rights adviser who might be working in the institution or an advocacy agency or whatever. At least there would be an indication that the person is entitled to apply to the board. There are two sections under the capacity part of the act, and I've suggested a number, and of course there could be renumbering at third reading for that.

There's a similar one here with respect to applications to the board in section 35. I suggest a new section right after that, and a similar suggestion with respect to admission to care facilities, in that part of the act, and on the second page, with respect to personal assistance plans.

You'll notice that in addition to the written notice that a decision is being made, that there's a right to appeal or make application to the Consent and Capacity Board, I have suggested that the person has a right to legal services or legal assistance. I tackle that directly—this suggestion, anyway, tackles it directly—in the final section, 73, of the draft HCCA, that the board may direct the public guardian to arrange for legal representation for a person who has made an application or is a party to an application before the board.

I have in mind here the analogy of the official guardian's practice with respect to family court actions involving children, where in a wardship or a custody matter in family court, the official guardian traditionally has provided representation for the child in question. I think a similar arrangement ought to be made for vulnerable persons in various institutions and so on under the Health Care Consent Act.

I added a very small section for your consideration. Subsections 73(4) and (5) amendments have to do with the provision of written reasons, which I think is done in most tribunals with which I have experience and I think it's very helpful to have that. Really it can be done quite simply, I think.

With that, as I say, this could be a very brief brief, I'm open for questions or discussion.

1410

**Mrs Johns:** Thank you very much for your presentation. I just have one quick question that I wanted to ask you. I'm sure my colleagues will have more. When you were talking about the written brief, I'm interested in that. We've heard it from a couple of people and I've never had the opportunity to ask the question on that. I understand that in the past there was a time delay as a result of the written brief. Can you tell me the reasons why you would like to have it and the timing that has gone on in the past, and just give me a little history about that, if you don't mind.

**Mr Wright:** Are you asking about written decisions?

**Mrs Johns:** Yes.

**Mr Wright:** I find it most helpful, speaking just as a person who goes to a number of different tribunals in the province, to have reasons for the decision made. I think it's a good discipline for the board itself to clarify why it's making a decision one way or another, and it's of course helpful to the person who is directly affected by that decision. I think it's as simple as that. I don't think it's an onerous requirement on the board to write down those reasons.

**Mrs Johns:** In the past they've obviously known the reasons but it's the written part that you're—

**Mr Wright:** Well, I'm not sure.

**Mrs Johns:** They sit down and talk to the people when they have these board hearings.

**Mr Wright:** I'm not sure that you always know the reason. You know the result, but you might not know the reason for the result. If the decision is, "Yes, you're incapable," or, "No, you can't have your own personal representative," that's just the result, that's not the reason why. It's not very helpful to the person.

**Mr Clement:** Just to follow up and then have my colleague have the floor, in your experience on the board, do they look at the cases on an individual case-by-case basis or is there a pattern or precedent, given a certain situation, and they review what had been decided in the past?

**Mr Wright:** Looking at most of the boards—I have to add that because we don't act within institutions, I've not appeared. This is something that civil lawyers, private lawyers usually get involved with, with the actual review board or the Consent and Capacity Board. But with other administrative tribunals, it is the invariable case that a written decision—it can be short, it can be in a kind of a form or sort of a rough outline, it can be a page or two, but it does outline the decision itself and the reason for the decision. I think in any kind of quasi-judicial situation, you really have to have that. In most cases a party will request it, but why not make it a rule?

**Mr Ramsay:** I really share your concern here and would like to see an amendment to the act that would accomplish this, and I thank you for giving us some actually good samples to use as amendments. As the government members have said, you've talked about having it in writing. Do you also think it might be important to have that also delivered orally by the health care practitioner who is making this decision?

**Mr Wright:** I'm speaking of the decision of the board itself. Normally, boards retire to make their decision and it comes out within a day or two days, depending on the workload of the different boards. Clearly the health practitioner would advise the patient directly of the decision, but I think putting in the full notice there in those suggestions that I've made gets a kind of regular pattern. The regulations actually could—work out a form for that, but it would make it an invariable case. I know how busy health practitioners are and will be, and to have something as an automatic thing that would be handed out that would be available of course for volunteers or other rights advisers who might turn up the next day, they'll know what decision has been made.

**Mr Ramsay:** It's my understanding of the bill that when a finding of incapacity has been rendered by a



health care professional, she or he does not have to tell the patient that finding's there and does not have to notify that person of their rights to appeal that decision either.

**Mr Wright:** I think it should be a requirement that that be done, and I think it could be done quite simply and I don't think it would be administratively difficult.

**Mr Ramsay:** I think that's what we both would like to see, to do it in a simple way but make sure that people are aware of their rights, but not develop it in some sort of cumbersome bureaucratic fashion that will take time, but at least the message is delivered so the patient will know her or his rights.

**Mrs Caplan:** I'd like to follow up on that because I think that if you're going to hold the professionals and the providers free from any action and liability, there's got to be some accountability, aside from what everyone, I think, would just say is your right to know—your suggestion of a form that wouldn't require all the findings but just, "I communicated with the patient and told them of the findings and the reasons and I've notified them of their right to appeal," something as simple as that, sort of a statement by the provider which is then handed to the patient, and also let's them know of their right to appeal. That's what you have in mind?

**Mr Wright:** Yes.

**Mrs Caplan:** That's a very reasonable suggestion.

**Mrs Boyd:** At the present time, as you probably know, there is a form, and what has been happening and what the concern of medical professionals has been is that basically there is this form which they call "Mirandizing" the patient. We heard it read out by a health professional and we got a good clue how they do it, which is really not very helpful to anybody, and they're saying that's not helpful to the patient.

I guess your suggestion of a written form, yes, in law that would be protective, it would show that in fact something had been done, but it doesn't meet that need that I think is quite sincere on the part of health professionals, that in their relationship with their patients they're doctor and patient, not lawyer and client, and basically that they would need more flexibility than that to do this. There are some physicians who don't want to do it, (a) they don't see any reason that they should do it, but (b) they just think somebody else should do it if it's going to be done at all. So there are both of those kinds of attitudes coming forward at the hearings.

It seems to me that it's lack of natural justice, if nothing else, when someone is deemed incapable and is not given the information even if that's the case, and then treatments are decided upon for them by someone else. I'm curious to know whether, if these kinds of changes don't come, if there isn't a requirement for rights advice, you think that this would stand up to a charter challenge.

**Mr Wright:** I don't know. Charter challenges are immense undertakings, as you know, but there certainly is a case to be made. Last week you heard from, and I've had an opportunity to read a submission made on behalf of the Advocacy Centre for the Elderly.

**Mrs Boyd:** That's right.

**Mr Wright:** You are talking security of the person and I'm not the constitutional expert who might talk about

that, but clearly that is a possibility. I would hope that if the medical community felt they didn't want to be the bearer—that this would interrupt their relationship with their patient by having to say, "I've just decided you can't make a decision," then I hope they would argue with the government and with their own boards that there ought to be someone who can do that, who could come in, the rights' adviser, which is allowed for in the regulations.

**Mrs Boyd:** No. The rights' adviser is what is being abolished when the Advocacy Act is abolished. The issue is that doctors objected to doing it and so the government, in putting the Advocacy Act in place, made sure those rights' advisers were arm's length and independent and wouldn't interfere in that relationship between doctor and patient. Now the doctors are saying, "We don't want rights' advisers, that interrupted our relationship, but we also don't want to do it ourselves."

Basically, what we have here is a situation where virtually every consumer of medical services has come in front of us saying, "Of course we should be informed of our rights and of course we should be informed that we have a right of appeal and how to do that," but nobody wants to do it and this government is taking away the rights advisers who did do it. We're caught in this conundrum where there is a clear division between what consumers of health services want and what providers of health services want, and somehow what ends up getting lost is civil rights.

**The Chair:** Thank you, Mr Wright, and I especially thank you for taking the trouble to draft the proposed amendments to the bill.

1420

#### ADULT PROTECTIVE SERVICE ASSOCIATION OF ONTARIO

**The Chair:** We're departing from the order on the agenda, if we could. I call Mr Dan Casey of the Adult Protective Service Association. Welcome. Thank you for arriving earlier than your allotted time so we could slot you in. I hope you have enjoyed the hearings as much as I have.

**Mrs Johns:** And us too.

**Mr Ramsay:** No sarcasm from the Chair.

**The Chair:** You may proceed when you're ready.

**Mr Daniel Casey:** I would like to introduce myself. My name is Daniel Casey, and I'm the chair of the Adult Protective Service Association of Ontario. I represent approximately 170 APSWs across the province. I have been an APSW for the past seven years, with three agencies, which includes two years working for MCSS, completing the Mount Forest nursing home initiative. I have been active on the executive for the past three years and have attended the advocacy coalition meetings on behalf of APSAO.

The primary function of the Adult Protective Service Association of Ontario Inc is to provide systemic advocacy for both adult protective service workers across Ontario and developmentally handicapped people they support. The APS program was created in 1974 by the Conservative government in response to concerns that



adults who have a developmental handicap living in the community were in jeopardy of having their rights violated by citizens and professionals. The program is currently funded by the Ministry of Community and Social Services through transfer payment agencies. We work for a variety of agencies across the province.

For 22 years, APSWs have been advocating with and for developmentally handicapped adults, providing rights information, supporting them to learn the steps to effective decision-making, empowering and assisting them to plan and direct their lives within the community. It is important to note that unlike any other developmental service, APSWs receive their direction only from the individual who has the developmental handicap. As such, we come to this committee with a clear mandate to represent the people we work for, our clients, and offer our support to the submission of People First, Ontario.

We urge the committee to seriously listen to all groups of vulnerable people representing themselves or those representing under total direction of vulnerable people. These are the people that Bill 19 will impact in a very real and critical way.

Our brief is quite long, as you'll note, quite thick, so I am not going to go through the whole brief today. I will draw your attention to the articles at the end of the brief that talk about the vulnerability of developmentally disabled people in the province.

The Consent to Treatment Act and the Substitute Decisions Act were passed unanimously in December 1992, with a safeguard in place for the vulnerable people whose lives would be affected. The safeguard was the Advocacy Act. It can be reasonably assumed that if the Advocacy Act had not been part of the package with the Substitute Decisions Act and the Consent to Treatment Act, the government would have been under extreme pressure not to pass the legislation.

The rights advisers currently employed by the Advocacy Commission will finish their contracts at the end of March 1996. To date, there are no concrete plans as to who will be performing these roles in the future. It is somewhat reassuring to see that the Mental Health Act will continue to allow for the function of rights advisers, mainly the PPAO's office. It is imperative that subsection 72(4) state designation by the ministry only and remove the allowance for designation by a psychiatric facility of rights advisers.

It is unlikely, in our view, that vulnerable persons would be advised of their rights without prejudice if direct care and service providers are the persons issuing rights advice. By removing this provision, the act will continue to safeguard a conflict-free relationship between the rights adviser and the facility administering treatment.

For the duration that the adult protective service program remains in existence, APSWs will continue to provide quality, cost-effective rights advice to those individuals who have a developmental handicap and are being served with notice of guardianship application or whose capacity to consent to treatment is in question. They can only provide this role to those persons they become aware are in this position. Many developmentally handicapped adults will not receive the service of an APSW because there is no mechanism to allow for

access. They will be in the jeopardy of losing their fundamental rights as a citizen of this province with no assistance to understand these rights or information on how to exercise them.

I'd like to comment on the capacity assessment process. The base line of a capacity assessment is a person with a moderate to mild developmental handicap. I think that should be noted. That's very strong; there is a strong prejudice against people with a developmental handicap in this province that believes they cannot make rational, clear choices about their own health care.

To assume that volunteers or families are able to provide cost-effective quality rights advice is presumptuous. Programs such as the APSW program and the family resource program are often the resource that families under the strain of support of a developmentally challenged individual, in an often hostile system, turn to for advocacy. It is also presumptuous to believe that families are not abusive to their challenged members. We no longer can assume that the outdated family model presented by 1950s television actually exists or ever existed. To forge ahead with a mechanism for quality rights advice will create catastrophic implications in the lives of vulnerable people.

The bureaucracy of Ontario, as well as health practitioners, the courts and many other professionals, will also be impacted by the reality of vulnerable people being streamlined into guardianship. The economic cost of these systems will far outweigh the expenditure for paid rights advisers.

There is also implied in this system of change, as suggested by the amendments to the Substitute Decisions Act, that volunteers are cost-effective and can provide quality rights advice. It is true that often volunteers who are dedicated can act in the best interests of the person they are advocating for. However, without training and experience, volunteers can often do more harm than good.

There is no mechanism to ensure that volunteers will be adequately trained to provide all the information an individual or family needs in order to have informed consent. There is also a liability issue in relation to volunteers giving inadequate or inaccurate information. Will we expect to see volunteers covered by liability insurance coverage? When providing a service for free, can we expect volunteers to take on the burden of liability insurance? Who will coordinate the training and recruitment of volunteers? These questions clearly indicate that a system which does not provide adequately for the people working within it cannot adequately work for the people it intends to serve.

In the recent discussions with the government consultant on the repeal of Bill 19, it was indicated that the government is looking at issues related to the protection of vulnerable persons against abuse. I would like to draw your attention to the charts attached from the Roeher Institute, and to the Dundas-Stormont-Glengarry Developmental Services Centre special support group home program review, and an article from the Sault Star entitled "Harm's Way." They specifically talk about the abuse of developmentally challenged people within our system and by service providers.



The most telling point in the Roeher Institute's chart, which is a breakdown of the literature on vulnerable people and abuse, is that of nurses and aides in a nursing and intermediate care facility who were interviewed, 10% admitted to engaging in physical abuse of clients. Some 40% of those same nurses admitted to engaging in psychological abuse of clients. I don't think we can ignore that.

When we put people in situations where there is a great deal of stress—when I did the nursing home project, the nurse-to-resident ratio was one staff to 14 individuals. Under the Nursing Home Act, each person is entitled to a specific amount of time for personal care. If you have a seven-hour shift and one nurse with 14 people, that's one half-hour per individual for personal care per shift. It's hardly adequate for someone who is profoundly handicapped or a senior who is bedridden.

1430

I'd also note that during the press scrum following the first reading of Bill 19, one government minister was quoted as saying, "We know that service providers do not abuse the people they serve." That's quite simply not true. I believe you will see that this is clearly not the truth. Arm's-length advocates who have the authority of the minister to go into the houses of developmentally challenged individuals who report abuse is a fundamental protection issue. Oftentimes, service providers will block advocates from entering facilities and have threatened clients with eviction should they continue to engage an advocate. Protection from abuse is a right, not a privilege, and the repeal of the Advocacy Act has taken that right away. I would again draw your attention to the charts from the Roeher Institute which summarize the studies.

The government must institute a third-party rights information advice system within this act. It is terrifying to consider that the vulnerable person's only informant is the person who is attempting to remove their most basic rights.

Consider the following scenario: A person has kept their 35-year-old developmentally handicapped daughter at home since she was 21. She has already convinced her daughter that a tubal ligation would be a necessary operation, and this was performed two years ago. The step was a reaction to a binge the daughter participated in after having run away from home for a week. Now, 21-year-olds don't really run away; they elope. I can leave home and it's not running away, but when we talk about that in terms of developmentally handicapped people, they run away.

The mother now decides that she will file an application to become her daughter's substitute decision-maker for personal care. She lovingly asks her daughter if she has always been taken care of by her mother and whether she feels they have a good life together. She then states that she loves her and will always take care of her and do what is best for her. Because she loves her so much, she wants to make sure no one else can harm her—she wants to make it legal. The daughter of course agrees.

The assessor is visited. Due to the inherent conflict the assessor has—who pays the bill? the mother—the implications of the assessment are described in a manner that the daughter does not fully comprehend. She therefore

relies on the information her mother has given her of the assessment process and consents. The daughter cannot read or perform simple math equations.

She has been socially isolated and so has no social skills or awareness of many things in the community or the province. She has never had to make decisions on her own behalf, so she does not know the steps to make an informed decision. The week-long binge of alcohol and sex does not stand her in good stead when looking at her ability to make decisions that may lead to serious injury or bodily harm. At no time did she have access to a person who understands the process and could clearly, in a manner that she understands, inform her of this and her rights. An APSW, having learned of this, informs her of her rights and, with the woman's direction, assists her to challenge the finding of incapacity and have the guardianship removed. An assessor makes more money, and vulnerable people end up in court.

Service providers are now able to apply for guardianship by proving that no one else exists. What is the definition of a reasonable search for an appropriate person? Who will ensure that a reasonable search has been carried out? Many APSWs have supported individuals for years before family members have been located. This is quite often true with people who have spent long periods of time in institutions. One APSW noted, "I supported a lady for four years before we became aware she had living relatives," and that's often common. Again, a clear conflict of interest exists. No service provider should ever have complete control over an individual. The Ontario public guardian and trustee's office needs to assume the guardianship role in the case of no other persons willing or able—not a service provider. This is the safety net that the province has for vulnerable people. Again, we would refer to the articles in the appendix to see why service providers should not be given guardianship over a vulnerable person.

It is also imperative that no employee of a service provider act as guardian regardless of their lack of direct contact with the individual. In some agencies, it is policy to have group home staff act as consent givers to residents living in other homes run by the same agency.

The concepts of "best interests" and "quality of life" raise concerns for persons with a developmental disability. Did Tracey Latimer have quality of life? Was her death in her best interests? Who will define what quality of life is for a person who has a profound developmental handicap? Will we witness the resurgence of eugenics?

The most common issue faced by APSWs in the field is the coerced and sometimes forced sterilization of challenged individuals in the name of best interests. In some cases, the individual is not told that they will be having a sterilization procedure performed and will be told instead that they are having their appendix removed. Imagine living in a society that tells you motherhood is a desired goal and imagine being told you cannot have this. Developmentally challenged people are capable of being good parents. Sometimes they're better parents than you or I can ever hope to be. Any person who is able to deal with the prejudice of the community and still raise a child deserves praise, not sterilization.



How do we protect vulnerable individuals from the prejudices in our society when we use best interests models? It is not too long ago that we put people in institutions because we believed it in the best interests of those who did not fit the norms of society or whom we were unable to provide for. We have environmentally stunted generations of orphans, the deaf, the blind, persons with autism, epilepsy, cerebral palsy and developmental handicaps because we thought what we were doing was in their best interests.

We as a society tend to act in our own best interests, not in the interests of vulnerable people, and this piece of legislation clearly shows this. In the era of cost-efficiency and economic uncertainty, would we be better served and protected if we repeal all four pieces of legislation, Bill 74, Bill 108, Bill 109 and Bill 110, and return to the pre-1992 era and reconsider our intent? Vulnerable people would also be better served and protected. The Adult Protective Service Association of Ontario must ask the fundamental question, protection for whom?

**The Chair:** Thank you, Mr Casey, for your presentation. There's no time for questions.

**Mr Clement:** I understand that. Could I ask our researcher? I'm very concerned about the statistics that are presented in this presentation. If I might be permitted, because I know just from my own casual reading that some of the statistics that were mentioned have been criticized, I'd like to know in particular whether the researcher can research the Pillemar and Moore document that was referred to by the presenter, and I'd like to know what the definitions are in terms of the violence that has been cited. Is that permitted, Mr Chair?

**The Chair:** Yes. Is there any objection to that? We will have that for the committee as a whole.

#### DAVID EVANS

**The Chair:** Dr David Evans. Dr Evans has filed a written submission with the committee. Welcome. You have 20 minutes, sir. Please proceed.

**Dr David Evans:** Mr Chair and members of the committee, I'm Dr David Evans and I'm appearing today as an individual psychologist. I wish to thank you for the opportunity to appear before you today to comment on some of the aspects of Bill 19.

You should be aware that I have a number of credentials and accomplishments that put me in a position to comment with some experience on several of the provisions of Bill 19. I'm a professor at the University of Western Ontario and I teach clinical psychology to both undergraduate and graduate students. I'm a past president of the Ontario Psychological Association and a member of the government affairs committee of the association. I am currently the president of the Canadian Psychological Association. I have written articles on the acts that Bill 19 will repeal, revise and amend, and I have monitored their development and implementation on behalf of the Ontario Psychological Association. I'm a practising psychologist, an academic and a researcher. My area of research is directed towards the evaluation of quality of life and the factors that determine quality of life.

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At the outset, let me indicate that all my comments will be positive with respect to the modifications that will occur with the passage of Bill 19. I believe that the changes that are envisaged to the current legislation will clarify what is a somewhat chaotic process of consent and substitution decision-making for both clients and health practitioners. Many clients and health practitioners remain confused with respect to the current legislation and Bill 19 goes some way to simplifying the process.

First, I am pleased that under section 2 of the Health Care Consent Act, 1995, members of the College of Psychologists of Ontario are included among those professionals defined as "evaluators." Practitioners in psychology have been involved in the development and administration of assessment and evaluative instruments for approximately 100 years, since before the turn of this century. Evaluation is in fact the cornerstone of our practice and it is one of the areas in which all practitioners in psychology are skilled.

Second, I would like to compliment the authors of the legislation for including a definition of "plan of treatment" in section 2 of the Health Care Consent Act, 1995, and the attendant section 12 which permits one of the health practitioners dealing with the client to propose the treatment plan, determine capacity and ensure consent is obtained on behalf of all practitioners involved in the treatment plan. This will remove considerable potential confusion and redundant communication for clients who are already distressed by their health problem.

Third, the new list of persons who may give or refuse consent on behalf of an incapable person outlined in section 18 of the Health Care Consent Act, 1995, provides clarification of a number of issues that are unanswered in the current legislation. Of particular note is the identification of the relative rights of custodial parents and parents having only right of access to children in giving consent on their children's behalf. I assume that when a parent who has only right of access presents a child for treatment, there is an obligation on the part of the practitioner to determine the unavailability of the custodial parent or, on the other hand, to ascertain that the custodial parent would not object to the decision. With respect to the latter, it might assist practitioners if such agreements concerning treatment were included in separation and divorce custody agreements, when possible.

The final set of changes that I would like to comment on relate to the decision not to include section 14 of the Consent to Treatment Act, 1992, in the Health Care Consent Act, 1995, and to repeal subsection 66(12) of the Substitute Decisions Act, 1992. These changes would permit a person as defined in section 18 of the Health Care Consent Act, 1995, to consent to the use of electric shock as an aversive conditioning procedure with an incapable person. This ability of other persons to consent on behalf of those who are incapable is essential in those cases where such procedures are the treatment of choice to maintain the wellbeing of the client concerned.

In addition to the qualifications that I stated at the beginning of my presentation, I have administered, researched and written on the use of aversive procedures



in the treatment of clients with alcohol addiction and sexual deviations. While I have not used the procedures with clients with self-injurious behaviour, the principles underlying the use of the procedures with these clients are the same.

Unlike several procedures used by health practitioners, the theory behind the success of aversive procedures using electric shock in controlling unwanted behaviours has been well researched and is well understood. Electric shock is used in these procedures because it is safe, easily controlled and provides the least invasive impact on the client compared to other aversive stimuli. As a psychologist, I'm required by the standards of my profession to follow a strict protocol before administering electric shock to a client, including testing the equipment before it is used with the client. While clients are always permitted to discontinue aversive conditioning at any time, I have never, in the course of treating several hundred clients, had a client withdraw from such treatment.

What does the shock feel like? Those you who have had an electric shock in the past will know. Those who have not may wish to compare it to the act that we all carry out all too frequently; that is, touching a hot pan in the oven. The mechanism and the effect are the same: We remember not to repeat the self-injurious behaviour in the future. However, as you are all aware, some time in the future we will require a reminder. This will occur the next time we reach for the pan without a pan holder.

Those of you who had time last weekend to watch some of the Canadian figure skating finals will no doubt have observed the competitors engaging in what is called visual-motor behaviour rehearsal or mental rehearsal. If you did not observe the competitors using the procedure last weekend, then watch for it in Atlanta at the Olympics in the summer. What is involved in the procedure of mental rehearsal is the mental review of the complete set of motor actions that will be engaged in during the athlete's performance. When a therapist uses the same procedure with a client, it is often referred to as guided imagery. I would like to use guided imagery with you for just a moment.

First, I would like you to imagine that you have a helmet on and that you are in a straitjacket with your arms secured behind your back. Try to imagine yourself in this scene as vividly as you can. Imagine also that you have been like this all day. Despite the restraint, you still try to strike your head with your fists.

I'd like you to set this scene aside now and relax for just a moment. Next, I would like to imagine that you are not restrained and that you have freedom to move in your environment. Imagine that although you have not beaten your head with your fists for several weeks, you get an urge to do so. You act on the urge and you feel a very brief shock to your leg. The shock is similar to the burning sensation that you get when you touch a pan in the oven without a pan holder. As with the oven situation, you stop the self-injurious behaviour and go on to do something else.

These two scenes are based on the life of Brian Singer, whom you have already heard about. Under the present legislation, the first scene represents daily life. Under the

proposed changes to the legislation, the second scene would represent daily life. I ask you, having visualized the two scenes only briefly rather than living them day in and day out, to consider which represents a better quality of life for clients who engage in self-injurious behaviour that has not come under control by any other procedure.

I would hope that you would support these changes which permit a concerned parent or other party to consent to this treatment on behalf of the incapable person, thus enhancing his or her quality of life immeasurably. Thank you.

**The Chair:** Thank you, Dr Evans. Each caucus has three minutes. Mrs Caplan.

**Mrs Caplan:** This legislation would permit faradaic therapy as a diversion technique to be done in your office outside of a Comsoc facility. Do you have any problem with that?

**Dr Evans:** No, I don't. I think it's pretty essential that that happen, because I have used it in my office with alcoholics, sexually deviant clients and so forth. So that I think to restrain it to Comsoc facilities—now I think the difference probably is going to be that in a Comsoc facility, the person will be incapable, hence someone else will have to make the decision. In my office, it's usually the client who will agree or not agree to the treatment.

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**Mrs Caplan:** I guess it would be possible for someone in a Comsoc facility actually to go out with their family for an afternoon and stop by your office and have the treatment, wouldn't they, with this legislation in place?

**Dr Evans:** The question is whether I'd be working on that particular afternoon but, anyhow, I presume it would be possible.

**Mrs Caplan:** Do you think, for people who have been found to be incapable of making treatment decisions on their own, that perhaps an appeal to a board such as the Consent and Capacity Board before a treatment like this is permitted outside a Comsoc facility might be a reasonable limitation?

**Dr Evans:** I think the difficulty with that is that it makes the possibility for the treatment rather elaborate. I think also it assumes that those who may consent on behalf of the other individual may not have their best interests in mind. I think, as in any other situation, the practitioner would brief them fully on the pros and cons, the difficulties and the possibilities associated with the treatment, and one would hope that they could make a reasonable decision. In actual fact, if I may just add a clause—

**Mrs Caplan:** Yes, just add to that as you're answering the question. Under this legislation, practitioners would be free from any liability for offering treatment and so would the person who's consented on their behalf, even if it should be found in the future that they weren't acting in the best interests of the person who was incapable. Does that cause you any discomfort?

**Dr Evans:** That perhaps; I think we should all be liable for the activities that we engage in. I've always assumed that there was a possibility in the courts to pursue me if I inappropriately administered a treatment.

**Mrs Caplan:** The other thing is the government has stated very clearly that any time a problem's come up,



they can deal with that by regulation. There's no requirement here in the legislation for there to be any consultation on regulations, for the regulations to be gazetted or people to be notified or have any waiting period. Do you think it would be a good idea if there were a requirement in the legislation that before they brought in regulations, either there should be at least the opportunity to have them publicly made available in a waiting period before they're implemented, or also perhaps some mandatory consultations? So much seems to be left to regulations. Does that concern you?

**The Chair:** Thank you, Mrs Caplan. If we could go to Mr Marchese.

**Mr Marchese:** Thank you for your presentation. I have a question which arises out of the comments you make around changes that you're happy about, which permits one of the health practitioners dealing with a client to propose a treatment plan, determine capacity and assure consent is obtained on behalf of all practitioners involved. Then you say, "This will remove considerable potential confusion and redundant communication for clients, who are already distressed by their health problem." I appreciate the fact that in some ways this simplifies it for the government because they say having one person instead of three is easier, it's easier having one than having three, and that it simplifies the process.

We've heard a number of individuals in the last week and a half, and organizations, who are very concerned about this. You have doctors or evaluators on the one hand saying, "This is really good, we thank you, government," and a number of people seriously concerned about the ability of one evaluator to make that assessment because of possible biases, because of the inability perhaps in some cases, for one person to have the whole total picture of what it takes to evaluate an individual. Unlike a court of law, where you might have a judge and 12 jurors, in this case you would only have one person dealing with the matter.

A number of people are very, very concerned about having one individual determine their life and so there is considerable contrast between yourselves and individuals who are very frightened about that. I'm not sure what your response to it is, but I'm very sensitive to their concerns.

**Dr Evans:** If I can respond quickly. I think, first of all, the assessment issue—it seems to me that all practitioners are supposed to be able to assess capacity, and if we can't carry that argument then some practitioners, perhaps, shouldn't have the ability, and not be on that list at the front. That's my first reaction.

The second reaction, having been a patient on a cardiac unit where I think it wasn't three, it was about 10 different practitioners dealt with me—in that day they didn't have to do this. To have them all seek consent every time, and on the day that I went to surgery, would have been very confusing and overwhelming. I had enough to grapple with and I would have preferred an individual.

The other point I would make is that that individual usually represents a team decision. The practitioners have all sat down and caucused with respect to what treatment plan are we going to pursue.

**The Chair:** Thank you, Mr Marchese. Mr Klees.

**Mr Marchese:** Is that three minutes?

**Mrs Boyd:** Is that our time? I'm sorry.

**The Chair:** Yes, three minutes.

**Mrs Boyd:** A very short three minutes.

**The Chair:** Well, it was a very interesting question.

**Mr Klees:** Thank you, Dr Evans, for your presentation.

I would like to also thank you for a very logical presentation on the electric shock treatment. We, as you know and as you mentioned, had a presentation from Mrs Singer on this, a very moving one indeed. I have a couple of question for you, though, with regard to this.

We have had presentations made to this committee over the last couple of weeks from people who have been opposed to this and in the context of their presentation have used the term "cattle prod," in describing this procedure. When I hear this it strikes me in a very grating way because it seems to me to be demeaning a procedure that may be appropriate for some, and I'd like your comment on the appropriateness of describing this treatment, that obviously helps some people, that way. Does it add to the discussion in a positive way?

**Dr Evans:** No. It seems to me, logically we use cattle prods with cattle, and I would hope that we use treatment apparatus with clients who are human, so I would be very upset if any person working with me would use that terminology and I would actually be upset at others. This is a treatment that has a tremendous impact for those few individuals who need it, the impact being that they have a better quality of life as far as I'm concerned.

**Mr Klees:** Thank you. I have another question for you with regard to using the treatment in facilities outside of Comsoc facilities. Do you in your practice require a release statement signed by people with whom you use this? Do you think that would be an appropriate way of providing some guidelines? Also, do you think it would be appropriate for legislation to require colleges to incorporate some guidelines for the use of this treatment?

**Dr Evans:** In terms of the consent, I always have a signed consent when I'm using this procedure. I think it simply protects me and it's very specific as to what will happen.

In terms of the colleges, I think that's reasonable. Certainly the college of psychology—we're required to obey a number of standards and those standards would take us back to the set of guidelines for the use of this procedure which are in the literature.

**The Chair:** Thank you, Mr Klees. Thank you, Dr Evans.

**Dr Evans:** Thank you.

**Mrs Johns:** Mr Chair, I'd like to just have a point of clarification: In the question that Mr Marchese asked, the section that they were talking about was section 12 with respect to one health practitioner being able to propose a plan for a number of people, not section 71, as Mr Marchese was talking about, which is the one-person board versus the three- or five-person board. I just wanted—

**Mrs Caplan:** What page is that on?

**Mrs Johns:** I don't have a page—the same as you said, section 12 of the HCCA.



**Mrs Caplan:** I've got it. Because there are so many different acts in here, you've got to reference an act.

**Mrs Johns:** HCCA, section 12 as opposed to section 71. When he asked his explanation he asked it about 71 when the paper actually referred to section 12.

**Mrs Caplan:** My section 12 on page 70 refers to a plan of treatment.

**Mrs Johns:** Yes. "If a plan of treatment is proposed for a person, one health practitioner may, (a) propose the plan of treatment...."

**Mrs Caplan:** That's correct.

**Mrs Johns:** That's what this gentlemen was talking about in the second from last paragraph on page 2, as opposed to section 71.

**Mrs Caplan:** Good.

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### PSYCHOGERIATRIC COMMUNITY CLINIC

**The Chair:** Next listed is the Psychogeriatric Community Clinic, Victoria Hospital, Dr David Harris, psychiatrist, and Mr Patrick Fleming. Welcome, Dr Harris and Mr Fleming. We have 20 minutes which includes any questions, so please proceed.

**Dr David Harris:** I'd like to thank you for the opportunity of being able to speak to you today. My name is Dr David J. Harris and I'm the director of the Psychogeriatric Community Clinic here in London, Ontario. Our topic is geriatric psychiatry. I'm going to share the presentation with my colleague, Patrick Fleming, who is a social worker.

We welcome some aspects of Bill 19 but we still have serious concerns regarding the bill and its impact on seniors in the hospital and in the community.

I'm going to present you with a brief overview of clinical geriatric psychiatry. I will then describe certain clinical concerns that we have relating to the bill, and then Patrick Fleming will discuss some aspects of community assessment.

Geriatric psychiatry is a branch of psychiatry dedicated to the care of seniors with mental illness and their caregivers. Geriatrics is a very functional discipline, heavily concerned with quality of life. The diagnoses that we see include both major and minor depression, delirium, which is acute confusion, dementia, paranoid or delusional disorders, family dysfunction and so on.

There are three groups of elderly people that we see with mental disorder. Firstly, the seriously mentally ill who have grown old, and I believe you've seen some of these when younger in the TV hearings that I watched last week. Secondly, and this is a very different group from the group that you've probably heard about mainly, are elderly people who have become mentally ill for the first time in old age. About half of all depression presents for the first time in old age, and obviously, most dementias present in old age. The third group that we also need to be aware of are those people with mild to moderate mental illnesses whose illnesses may nevertheless seriously impair the ability of others to care for them. For example, minor depression may seriously impair the ability of the patient to cooperate in rehab or even to cooperate with a home care program.

If you look at Roth's figures, about 19% of the elderly suffer from significant mental disorder and another 21% minor degrees of disorder.

There are also some social realities that we need to recognize when we look at this population. Most women in old age are widows, most males are still married, a quarter have no surviving children, so putting the responsibility on the family may not always be realistic because there may be no family. Indeed, many of the children may themselves be seniors. Last week I saw a man of 75 who reminded me that I'd seen his mother-in-law the previous week. Indeed, I had. She was 95.

I work in the community clinic here in London, Ontario. We see about 500 new cases a year and have an active caseload of another 500 cases at any one time. The clinical staff consists of one psychiatrist—myself—two social workers and one and a half nurses. Indeed, we carry the heaviest caseload of any program of its type in the province of Ontario and currently run a two-month waiting list.

We see about a third of patients in the office, but two thirds are seen outside the office: a third in their own homes and a third in nursing homes or homes for the aged. We also do about 10% of our work doing ward liaison work where we visit medical and surgical wards doing liaison with our colleagues there.

We have no inpatient beds of our own and are therefore dependent on our general colleagues, such as Dr Velamoor, who you'll hear from shortly, next time, in the general hospital, or for selected cases going to the provincial psychiatric hospital. Incidentally, the absence of psychogeriatric beds in a general hospital is a great deficiency, because so often one is dealing with both medical and psychiatric pathology in old age.

Some general principles I think that you need to recognize in legislation: Legislation should reflect societal values and may influence them. Legislation may lag behind scientific knowledge, and I think this is one of the purposes of these meetings here today. Medicine should care always and cure sometimes. Legislation should not impair that care/cure model.

Most mental health legislation, particularly in the Canadian provinces, was originally very heavily hospital-based and only now is legislation beginning to look at community issues. There's certainly a need to enhance geriatric aspects of legislation.

General adult psychiatry interfaces with society and to some extent medicine, but geriatric psychiatry interfaces very heavily both with medicine and society. Thus the medical model cannot be ignored and multiple pathology is the rule. Even in our own clinic, which is an outpatient, outreach program, 92% of the patients seen by us had major medical problems requiring consideration in the psychiatric management.

Why is geriatric psychiatry important, and why should legislation reflect clinical reality? Firstly, psychiatric illness is common among the elderly with acute medical conditions. Undiagnosed depression may lead to suicide, either active or passive. One third of all patients over 65 admitted to a general medical ward in a general hospital will be confused during part of their stay, and that is double the adult rate. So the psychiatric management of



delirium is a very real issue that has to be dealt with on a daily basis in any general hospital.

Eighty per cent of the nursing home residents in Ontario have a psychiatric diagnosis, half of which is dementia. Shulman has described the Canadian nursing homes as "the new mental hospitals for the aged." Yet half of all nursing homes in southern Ontario have no visiting psychiatrist. There is a real deficiency of clinical services to this section of the population.

A quarter—27%—of provincial psychiatric hospital beds are occupied by the elderly, and in Middlesex county, which is where we are now, where 14% of the population is over 65, 35% of all hospital discharges are elderly.

You're devising legislation that presumably will take us into the next century. Let's look at some realities to show how important a topic this is. We're dealing with an aging population. Putting it in context, if we look at the 15-year frame from 1986 to 2001, the general population rises 17%, females over 85—these are the people who are going into nursing homes these days—rise by 81%, and this issue has not yet been adequately addressed either in health care planning or indeed in legal planning.

What modalities of intervention are we involved in? We may see patients in consult only, and that is usually a team assessment: myself plus other members of my team such as Patrick Fleming. We also take patients on in treatment, which may involve pharmacotherapy, in the community, group therapy and so on. We have to liaise with various other groups, including home care. We have to deal or liaise with our physician colleagues in other areas of medicine regarding medical issues, and frequently we come into legal issues as well, mainly to liaise, for example, with the family lawyer.

What are the main issues as they relate to the legislation? This is in the printed handout that you have.

Firstly, it should be normal clinical practice to tell most patients found not to be competent one's findings. It should, however, be possible to use one's clinical judgement to decide how and in what manner this message is conveyed to the patient. If the psychiatrist is in any doubt as to the extent of the disability, he may choose to actively suggest that the patient may wish to appeal, if he so wishes, and advise him accordingly. This is not appropriate for most patients who are found to be grossly demented or delusional; particularly if they've been previously highly functioning, they may be genuinely distressed by having this finding rammed home to them.

Secondly, and this is very relevant to an omission in this Bill 19, specialist clinical teams such as our own, if properly staffed and trained, should be in a position to assess competence and issue appropriate certification, including outpatient certificates of incompetence. These were not restored in Bill 19 and they had been taken away by the previous legislation.

Under current legislation, who requests and who pays for capacity assessments still has to be clarified. Particularly in the absence of outpatient certificates of incompetence, this is a very serious problem at the present time and frequently interferes with patient care.

This is a comment that was raised by some of my inpatient colleagues: Under the current legislation, delays in getting substitute consents may be a very real problem and delay recovery. In the case of the elderly, delays may be very damaging to health. One of my colleagues described a patient admitted to hospital yesterday who is actively delusional, is aggressive and cannot be treated until the rights adviser comes to see him today. So this man, who could be your grandfather, is going untreated in a hospital in this province.

Incidentally, I did an audit of such cases about 10 years ago in Victoria Hospital and found that as soon as appropriate medication was instituted, these people really regained their freedom very quickly; they didn't need to be restrained within a 24-hour period. I think there was one in 100 whose restraints lasted longer than a 24-hour period.

We do have concerns regarding the use of volunteers in the PGT office. We would also like to clarify the ability of the PGT to participate in "do not resuscitate" orders. At the very least, this should be available as part of the treatment plan, and every attempt, when a patient is competent or of variable competence—that's a very real clinical reality—should be made to ascertain the patient's own wishes. One very much wishes to avoid the situation where a patient with terminal cancer is resuscitated, only to die again a few days later.

#### 1510

The law must accept that at times, albeit in a minority of cases, the next of kin or the decision-makers may not be competent to carry out their role. This creates problems in a program such as my own, particularly in the community where we're, in a sense, in a least-restrictive environment.

Certified social workers should be given status as health care evaluators, as they provide such a vital service within the context of most team assessments in this field. Patrick will talk about that later.

The major efforts of advocacy activity should be directed at high-risk cases, specific cases where errors of judgement or management are raised and particularly where family conflict is evident. Advocacy should also address the issue of systemic advocacy, and the latter should be clinically appropriate and aware. Incidentally, geriatric education, which has expanded in the last few years in the medical schools and the nursing schools, would really be the route to go to yield most benefit.

Obviously an appeal system is necessary, but do bear in mind that that time and those dollars are less available for direct patient care. I'd point out that there's a shortage of psychiatrists in this province, and there's certainly a worldwide shortage of geriatric psychiatrists, therefore one has to be aware of the clinical realities when it comes to using, say, the psychiatrist's time.

Many, if not most, physicians have found the current legislation too complex for clinical practice. They frequently avoid issues as they do not know where they stand. They feel in a legal minefield and, at best, they may just treat anyway.

Just a very quick vignette, and it's not in the handout because this cropped up only this week, just to illustrate the realities in which I work:



For several years, I'd been involved in monitoring an elderly eccentric lady. She would not bathe herself or wash her hair and she lived on grapefruit and yoghurt. She repeatedly refused medical care. She was in hospital a few years ago when we thought she might have a cancer, but this was ruled out and we could not detain her further, and she lapsed back into a state of self-neglect.

A year ago, she collapsed and refused assistance from the ambulance attendants. They were bound by her expressed wishes and so she was not taken to hospital. I continued to monitor this lady at home roughly every two or three months. About a year later, after discussion with the family member, I felt that once again we might have reached a time when maybe we could intervene. This decision was partly arrived at because of the aging of the caregiver, so there's a second player to be considered now in this situation. He's over 80, by the way. We certainly knew that she was not viable at home without his support, so if he died, she would certainly be a problem.

I therefore sought the opinion of a colleague who has inpatient beds, and this request was answered fairly quickly, within two weeks; this was to assess a problem that's been there for years. As it happens, during those two weeks she did collapse twice again and she refused treatment, so the husband did not call an ambulance. My colleague went to see her the other night. There was an ambulance there and she was dead.

My regrets with this case are, firstly, that she may well have had a treatable medical disorder; but more particularly, the quality of her life was significantly impaired in the last several years, and with compulsory treatment—her life was not in danger at that time—we could have improved dramatically not only the quality of her life but that of the caregiving family member.

**The Vice-Chair:** Thank you, Dr Harris. We've got about two minutes. Oh, we're not finished? You're going to continue?

**Dr Harris:** I thought I had 10 minutes, sir.

**The Vice-Chair:** Yes, you do, absolutely. I assumed you were finished and we were going to move to questions, but if you want to continue, go ahead.

**Mr Patrick Fleming:** Community assessment; I'm wanting to focus on that. Most situations that create concern around capacity of an individual, personal or financial, are not observed in an inpatient setting. With shorter inpatient admissions and rapid discharge planning, this lessens the chances for inpatient care teams to witness the discrepancy in behaviour.

Most often, it is in the community where the individual lives that changes with coping skills will begin to create concern. Also, unless the change in functioning is gross in nature, it is vital to assess individuals in their own environment to see the level of functioning in a familiar setting.

Health care practitioners, physicians, nurses, occupational therapist, psychologists and many others, along with social workers, have been doing assessments in the community for years. Emphasizing equal importance with assessments on an inpatient or community basis will reflect the new realities of health care.

The profession of social work is unregulated in the province of Ontario. Under present legislation, professionals regulated under the Regulated Health Professions Act are designated as health care practitioners and can take part in the assessment of the individual. Often, social workers are significantly involved with the psychosocial assessment of an individual, both on an inpatient and community basis. Their clinical findings play a critical part of the assessment; however, they cannot be one of the authors. It is an unbalanced use of an important professional resource.

**Capacity assessors.** Under the present legislation, professionals and agencies are unable to assess individuals who have had contact with them. In large agencies, for instance hospitals, service areas are often quite independent of each other; therefore, little risk of conflict of interest. The professionals involved, guided by their professional standards of practice, would minimize conflict of interest. With specialized assessments, resources to complete them may be limited. Unnecessary delays may take place with situations that are quite vulnerable.

It would be a good use of resources to enable professional personnel within agencies to assess individuals who have had past or present contact with the agency. If a second opinion is requested, then different professional personnel could be used.

**User-friendly information.** In a final comment, individuals, family members, professionals and the general public find the issue of capacity assessment quite confusing. It would be very beneficial to have a simply worded flow chart to visually demonstrate the process from start to finish. It could highlight how to start, who becomes involved, who pays, individual rights, outcome from assessment, appeal mechanisms etc. This would allow a better understanding and use of the resources available.

**The Vice-Chair:** Thank you. We'll move to questions now. Each caucus has about one minute. We'll start with the third party.

**Mrs Boyd:** Thank you, Dr Harris and Mr Fleming. I always learn more every time I hear you, so thank you for coming. I was following you just fine until you came to your example. I guess that's where we fell off the wagon, because I take it that you do not think that a person's expressed wish should take precedence over a medical opinion as to whether that particular illness ought to have been dealt with whether the patient wanted it to be or not.

**Dr Harris:** There were two parts to my concerns with that patient. Firstly, her expressed wish was not to be treated. This was probably based on her fear of doctors and hospitals. I'm saying that's something that happened, and you can argue whether that should or shouldn't have happened. The second point was that she had a miserable last 10 years of her life. Her husband, who is the only other member of her family in this country, has had a miserable last 10 years of his life. I think that we could have, with some compulsory powers, enabled her to lead a normal life and possibly live longer. But it wasn't the living longer that was worrying me; it was the quality of life.

**Mrs Boyd:** We believe that the Advocacy Act would do that. An advocate could have intervened.



**The Vice-Chair:** Ms Boyd, we have to move on.

**Mr Parker:** Thank you both very much. Dr Harris, in your paper you've made a few comments and recommendations on the subject of assessors, particularly the qualifications for assessors and the appointment of assessors. Under the present act, that's a matter that's handled by way of regulation, and frankly, that's not going to change; it will be handled by regulation under the proposed bill. Your comments and recommendations will be very helpful to us in establishing the regulations under the proposed bill.

Tell me, were you consulted on the establishment of regulations under the current law?

**Dr Harris:** I was not personally. I don't know whether OPA was consulted. I heard Brian Hoffman talking to you last week on television, but I was not personally consulted. I've been quite active in OPA and in CPA.

**Mr Parker:** Thank you very much for your assistance to us. That will assist us in establishing the regulations under the proposed bill.

**The Vice-Chair:** Thank you, Mr Parker. To the Liberal caucus, Mrs Caplan.

**Mrs Caplan:** I want to thank you. Over and over again we've heard, from most of the people who've appeared before the committee, your first point: that it should be normal clinical practice for people to be told.

The other thing we've heard, frankly, is that psychiatrists who are used to dealing with the Mental Health Act are comfortable with that and they know how important that communication is. Our concern is that if there is not that obligation somewhere to do that, then people are denied important information.

While there's the black and the white, where it's clear that those who are totally demented and are comatose or whatever are not going to be able to comprehend—those are the clear ones; nobody has a problem with those—and where you're clearly competent, there's that whole grey area, where you may be going in and out of competency, where communication is so important because it can lead to, and I've seen it from personal experience, "You're keeping something from me." In fact, if you are keeping something from them and they find out you've kept something from them, it makes their condition worse. Have you had that experience, where finding a way to communicate can actually be therapeutically beneficial?

**Dr Harris:** Can I address that? It depends on the disorder you're dealing with. If I can give you an example of manic-depressive illness, when I have manic-depressives who are well I will spend a considerable time discussing with them what I did to them when they were sick. I detained them. As I'm the outpatient doctor, I might not have been the treating doctor. They usually say: "That's fine. Please do that next time if it's necessary." Then I feel far more comfortable when I have to do the same thing again a year later.

**The Vice-Chair:** Thank you, Mrs Caplan. Sorry, we're out of time. Thank you very much, gentlemen, for the presentation.

1520

**Mrs Johns:** Mr Chair, I just want to make a point of clarification. I know I've done this before, and if everybody's got it, I'll just go. In section 2 of the Health Care

Consent Act, the "health practitioner" definition: As we all know, the social workers aren't with a college or a registered body yet, so they can't be outlined in there. They would have to be part of clause 2(1)(t).

"Evaluator," in the same light, can't be outlined under "health practitioner," where we're drawing our definition from, and it would have to be prescribed by the regulations as evaluators. It's not to say that in this act we're not taking social workers as evaluators; it's just because they have not been able to form their own college or register yet. We deem that social workers will be a very important part of the evaluator process.

#### LONDON AND DISTRICT ACADEMY OF MEDICINE

**The Vice-Chair:** The next presentation will be the London and District Academy of Medicine, Dr R. Velamoor and Joy Wendling, please.

You have 20 minutes for your presentation. You may want to leave some time for questions at the end. You can begin any time.

**Dr Raj Velamoor:** We appreciate this opportunity to be heard, because we believe that participation in the planning process is extremely important so that we can work together. Also speaking today is Ms Joy Wendling, who is a paralegal adviser at St Thomas Psychiatric Hospital. Dr Chandarana is unable to be present today. He has requested that I forward to the committee his summary of a recent survey of physicians to gauge the reaction to the Consent to Treatment Act.

We are thankful to the London and District Academy of Medicine for arranging this time slot so that the comments and concerns of the department of psychiatry at the University of Western Ontario could be presented to this committee.

Our presentations will focus on the general adult psychiatric services, which means the age group of 16 to 65. At the very outset, I would like to state that we support the changes the provincial government is introducing to the Consent to Treatment Act, Advocacy Act and Substitute Decisions Act. The government has corrected some of the imbalances the acts created and also removes the several layers of costly bureaucracy.

We believe that Bill 19 deals with the issue of informed consent in a practical and realistic way, while maintaining the rights of patients to make informed choices about their own care. The new act also strengthens the role of families in making treatment decisions on behalf of incapable relatives and improves the relationship between care providers and their patients.

The doctor-patient relationship, in my view, is critically important in the overall management of psychiatric patients. Treatment alliance between the doctor and the patient is founded on trust. The advocacy system has created an adversarial climate which covertly promotes lack of trust between the doctor and the patient. What is often forgotten is the fact that every individual in psychiatric distress has also the right to receive the best treatment so that his health interests could be safeguarded.

In the new act, the list of substitute decision-makers has been streamlined. The definition of "emergency" has



been clarified to include a person who is "apparently experiencing severe suffering." Proposed changes to the Substitute Decisions Act should make it easier for families to assume decision-making authority for their loved ones. We endorse the provision in the new act for the possibility of a substitute decision-maker to consent, withhold or withdraw treatment in the patient's best interests.

Here are some of my concerns which I hope can be addressed so that we will have a happy compromise between what we had and what we might get:

(1) We are concerned that we may be moving too quickly from a mode which was bureaucratic, adversarial and expensive to a model which places too much responsibility on family members without adequate supports available to them.

(2) The new model is a medical model which does not adequately address the specific concerns of psychiatric patients. For example, several of our patients are cared for in the community by rehabilitation programs and other outpatient services. Some of these patients are non-compliant and are unable to be helped until they actually decompensate and become certifiable.

I couldn't agree more with Dr Harris's earlier comment that sometimes it's very difficult to bring them into hospital for the simple reason that we just don't have the beds. There are far too many people chasing too few beds.

(3) Although the new act has amended the definition of "emergency" to include a person who is "apparently experiencing severe suffering" which will put the patient at risk of sustaining serious bodily harm, there is no mention in the definition of "risk to others" due to aggressive behaviour on the part of an individual also requiring urgent intervention. This might be because the definition of an emergency is a medical one, and does not perhaps capture the psychiatric perspective adequately.

(4) The Health Care Consent Act allows those who have been found incapable to apply to a tribunal. It is not clear who will assist these individuals to make this appeal. One wonders whether they'll have the ability to do it themselves. Who will, therefore, assist those individuals and how will they be paid?

(5) The Health Care Consent Act, under 19(1)2: "If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish"—that's what I'm going to comment on—"the person shall act in the incapable person's best interest." While we recognize the value of this provision, the family will need considerable assistance and support in this respect because I think that is a great deal of emotional burden on the family.

(6) It is unclear in the new act whether a substitute decision-maker can consent to personal assistance services in a hospital. For example, patients who are in a psychiatric hospital receive assistance with routine activities of daily living, nutrition, shelter, clothing etc. This is in addition to treatment. It is unclear whether a substitute decision-maker can consent to such personal assistance services in a hospital.

In conclusion, I would like to commend the government for making much needed changes to the consent, advocacy and substitute decisions acts. Hopefully, we will design a new model that facilitates treatment without delay while recognizing the right of the individual to question decisions regarding their management. I would like to emphasize that every support should be made available to the families of psychiatric patients in helping them make the best decisions in the best interests of their loved ones.

I would at this point like to hand you over to Mrs Joy Wendling.

**Ms Joy Wendling:** Over the past decade a great deal of emphasis appears to have been placed on one's right to refuse treatment. Many health care practitioners have been concerned about a person's right to be treated, even when one's illness leads to a belief that treatment is not necessary. Bill 19 goes a long way towards finally attempting at least to balance these rights.

The main problems with the existing legislation today are that it is complicated to follow and cumbersome to implement. Many of the changes included in Bill 19 will solve these problems and we applaud and endorse them. These are listed in the part of our written submission that is called "Discussion of Legislation." I'm not going to read the whole thing out to you. I would just like to highlight a few of our concerns. I'll refer to the numbers on that discussion of legislation as I go through my discussion.

Items 1 and 2 of the written submission deal with welcome changes regarding treatment and treatment plans. When one is dealing with a capable patient, consent is relatively easy. The health practitioner informs the patient about his condition and proposes treatment. The patient consents to the treatment or refuses it. When minor adjustments in the treatment are required, this is quickly explained to the patient and consent obtained. The patient may also consent to the withholding or withdrawal of treatment, particularly do not resuscitate, recognizing that sometimes treatment simply prolongs the pain and suffering while postponing the inevitable. Often minor adjustments are required before optimal treatment is found. We can easily obtain this with a capable person.

When the patient is not capable, everything becomes much more difficult. First, a substitute decision-maker at present can only consent to treatment, not to the withholding of treatment. Second, local general hospitals provide primary psychiatric care; provincial psychiatric hospitals provide secondary and tertiary care. This means that family, the usual substitute decision-makers, are at a distance from the hospital. When the patient is transferred to the psychiatric hospital, it is usually by ambulance and frequently family members are not present. It is in the patient's best interest to continue treatment, but at present we cannot do that until we obtain a new consent. This can take some time. It is also much more difficult to contact the substitute for a minor adjustment in the treatment. So we strongly endorse those proposed changes.

Item 3 of the written document, treatment seldom consists of one modality proposed by one health care practitioner. Many practitioners contribute to the treat-



ment plan. Current practice is to obtain one consent to the entire plan of treatment, but we do welcome the clarification of this in the legislation.

#### 1530

Item 4 addresses what I consider to be a very important issue. The Consent to Treatment Act is written, I believe, from a perspective of proposing a new treatment to a substitute decision-maker. This is appropriate in many cases, but in psychiatry capacity to consent is not always clear-cut. Patients can and do become incapable after treatment is initiated.

When that happens, we must obtain a substitute consent to continue the treatment. Stopping treatment until substitute consent can be obtained is at best detrimental, and at worst dangerous. While an argument could be made that subsection 16(3) does not apply to this situation because the terminology of the act is "begin," we believe that it should be clearer on this and actually specify that subsection 16(3) does not apply to treatment already begun with the patient's capable consent. Treatment should stop only if the patient is found by the board to be capable.

Item 5: One problem with current legislation is that it is not always clear who should provide consent when spouses are separated or when parents are separated or divorced. We have had cases of separated spouses insisting on being involved in making decisions. So section 18 will clarify this.

Section 71 would permit a hearing of the board with only one member. We believe that decisions made by the board regarding capacity to consent to treatment are extremely important and should never be made by only one person. With all due respect to the legal profession, unless a board member is one of the very small number of lawyers who are also health care practitioners, we do not believe they have the expertise to make a decision in isolation regarding capability to consent to treatment.

We strongly recommend that any board which is reviewing a health practitioner's finding of incapacity to consent to treatment must have at least one member with clinical experience and expertise in evaluating mental capacity.

Item 11: While I believe the intent of the legislation is to include personal assistance services provided in a hospital, a careful reading of the applicable sections of the Health Care Consent Act, which I have itemized in the written document, does not make it clear that this is the case. The definition of "treatment" specifically excludes a personal assistance device. Part IV of the act which deals with personal assistance plans applies to care facilities, not to hospitals. If the intent of the act is that personal assistance services can be provided in a hospital, and I certainly hope that is the intent, then this should be more clearly defined in the act.

Item 12: While the system of providing rights advice in the Consent to Treatment Act is cumbersome, and we welcome the changes about this, we believe it is still important that a person be informed he has the right to apply to the board for a review of a finding of incapacity. In the best of all possible worlds, the health practitioner who makes the finding will inform the subject of that finding and of her right to apply to the board. I believe

a majority of health care practitioners would do this. This is, though, an imperfect world and I believe the act should direct that this be done.

In our part II, "Substitute Decisions Act," item 1: We do not agree that a child of the grantor of a power of attorney should be allowed to witness it. Unfortunately, in our business we sometimes see the worst of people. There is a real risk that vulnerable, elderly patients will be coerced into signing a power of attorney by someone who may be able to benefit financially from it. It is minimal protection to prohibit children from witnessing the document. It is also minimal protection to require the witnesses to believe that the person granting the power of attorney is capable to do so. There are a great many vulnerable people in our society and we have a duty to protect them.

Item 2: Prior to the Substitute Decisions Act, I was frequently asked by family physicians and other health care providers what action they could take when they believed a patient was not financially capable. The answer was, unfortunately, none.

When I first learned that the Substitute Decisions Act would allow anyone to request an assessment, I believed we now had a solution for these situations. Unfortunately, it was decided that the person who requests the assessment must pay for it, and that assessors would set their own fees. Hospitals and care facilities are not prepared or able to pay for assessments. It is not reasonable to expect a health care practitioner to pay for an assessment out of her own pocket. I realize that this allocation of cost is not inherent in the act itself, but we strongly recommend that something be done to exempt health care practitioners from the fee for assessments.

Item 3. We do not agree that subsection 17(5) should be revoked. Someone should not be permitted to appear out of the blue, so to speak, and be able to obtain control of a person's property or person. Forgive me if I sound cynical, but I've worked in health care for over 30 years, most of it in chronic care and psychiatric care. This does happen much more frequently than any of us like to realize or to admit.

It is not mentioned in our written submission, but I should like to state that we also endorse the removal of registration and validation of powers of attorney for personal care. These provisions were unnecessarily complicated, and I have to admit I often felt like Alice in Wonderland when I was trying to explain it to staff and to families. Powers of attorney for personal care will be valuable only if they can be used easily when appropriate.

Part III, the Mental Health Act. We believe very much in the confidentiality of personal information, but it is extremely important in psychiatry that we have as much information about a patient as possible. Information from other health facilities can be obtained without the patient's consent through a request from the officer in charge. However, other agencies, such as the children's aid society and correctional services, require consent.

We deal with people who cannot or will not give consent, and often will not give us any information themselves. Often we cannot find a substitute to consent either. We recommend that the provision allowing the



chief executive officer to obtain information without the patient's consent be extended to other agencies. We must also have the patient's consent to release information to family physicians and community agencies who will be following up the patient. It is unrealistic to expect these people to provide care to the patient without adequate information, yet if for some reason we have failed to obtain a consent before the patient leaves hospital, we cannot provide it. We recommend that the Mental Health Act allow us to release information to anyone providing follow-up care.

Thank you for the opportunity to appear before you today to discuss issues that are of great importance to the health care field and especially to the field of psychiatry. We believe, with the exception of the few areas we've mentioned, that Bill 10 provides excellent revisions to the legislation which governs our daily lives.

**The Vice-Chair:** Thank you for your presentation. Each caucus will only have one minute for questions; we'll start with the government side.

**Mr Parker:** Thank you very much for your very helpful comments. We will pay close attention to everything you've submitted. I'd like to respond just to one at the moment.

On page 7 you comment on the obligation for payment for the assessment where it's the doctor who's ordered the assessment, and you're not the first one to raise that concern in practice in one way or another. One of the expectations we have is that we will expand the number of people qualified to provide assessments and will include, in the group of those qualified, people in salaried positions in clinics and hospitals and so on so there would be greater access to assessors able to carry out the required activities without charging for it. You give an example of where it might be appropriate to use a person of that sort. I hope my comment in response to your concern gives you some comfort, but I want you to know that we have heard your concern and we'll take it into consideration as we move forward.

**The Vice-Chair:** To the Liberal caucus.

**Mrs Caplan:** I find the comments from Mr Parker interesting. I'd also like to know what their plans are to ensure that there's appropriate training and certification for assessors, because I think quality assurance is important. I hope you would agree with that.

**Mrs Wendling:** Yes, I do.

**Mrs Caplan:** I would like to congratulate you on the very clear recommendation regarding the individual's right to know when they've been found incapable. I agree that the statute should be very clear about that, particularly given the fact that it has removed any liability from either the substitute or the practitioner who makes those kinds of findings and proceeds to treat. I think it's just a basic right.

I want to ask one small question on the issue of 17(5), which has been deleted. I wondered why it was taken out. It seemed to me that while there may be an exception, usually if someone's going to apply to be a substitute decision-maker they would have a relationship. If you get a chance to comment on that from your experience, I would appreciate it.

**The Vice-Chair:** Mrs Caplan, I'm sorry, you're out of time. You just had one minute and you chewed it up pretty quickly. We'll move to the third party.

1540

**Mrs Boyd:** It's indeed a pleasure to have health care providers coming and saying many of the same things consumers of health care have been saying. I'm delighted with most of what you've said in terms of the concerns you have. I would agree with you that the current process of registration and validation is cumbersome. We were assured it had to be done that way in order to be legal, so we're delighted that different advice has been given now.

I wanted you to comment on whether the addition to section 66 of "the following factors: Whether the guardian's decision is likely to... improve quality of the person's life" etc could interfere with the withdrawal or refusal of treatment.

**Mrs Wendling:** I don't believe so, given that the definition now includes withdrawing or withholding.

**The Vice-Chair:** On behalf of the committee, I want to thank both of you for your presentation.

**Mr Parker:** Mr Chairman, I just want to make the observation that the previous government obviously didn't consult enough when it passed its legislation.

**Mrs Caplan:** At least he's laughing when he says that. I do have a point I'd like to make.

**Mrs Boyd:** I'd like to make a point of personal privilege, if I may. The current government has consistently said it doesn't need to consult on this bill because we consulted too much.

**The Vice-Chair:** Ms Boyd, Ms Caplan, I'm sorry, this isn't time for debate. We're going to move on. The next speaker is Dr Sandra Fisnan from the Children's Hospital of Western Ontario. Is she in?

**Mrs Caplan:** While the next presenter is coming forward—

**The Vice-Chair:** Ms Boyd, please.

**Mrs Boyd:** I'm not saying a word.

**The Vice-Chair:** Ms Caplan. You see, now I'm getting all mixed up between the two of you.

**Mrs Caplan:** While they're coming forward I'd just like to clarify something.

**The Vice-Chair:** Hang on one second. Dr Sandra Fisnan wasn't scheduled to appear until 4 o'clock and she isn't here yet that I'm aware of. Can have unanimous consent to recess till 4 o'clock when she is scheduled to appear? Is that a problem?

**Mr Clement:** What happened to the 2 o'clock? They're gone?

**The Vice-Chair:** They're gone. Dr Fisnan is the last one of the day and isn't here yet and isn't scheduled to appear till 4.

**Mrs Caplan:** Mr Chairman, I suggest this might be a good opportunity for us to have some questions answered by the ministry people who are here.

**Mrs Johns:** Can I have a point of clarification about this presentation before we go on to that, and then you can ask some questions? Is that okay with you?

**Mrs Caplan:** Sure I wanted to clarify something as well.

**Mrs Johns:** Okay. In section 3 in this paper that Dr Velamoor presented, he talks about risks to others. I just

wanted to clarify that we talk about that in the HCCA portion of the bill under section 6. We're talking about the common law taking precedence with respect to someone who could cause serious bodily harm to someone else. I wanted to show you that it was considered and it is in the common law, so we are considering that person in that kind of situation with this act.

**Mrs Caplan:** I think there's also another application. If a physician deems the person to be a risk to themselves or to others, they can detain them under a form 1 under the Mental Health Act, so there is the double protection there. That's not changed by this legislation. I also, as a matter of fact, wanted to point out that there are two places that should respond to that concern that the previous presenter raised.

**Mrs Boyd:** Just in reply, I'm not sure that didn't answer, actually, the other example Dr Harris raised about the current problem he has in his own ward at the moment about a person who's untreatable. He did say that person was aggressive, and I was quite curious about why that hadn't been deemed to be an emergency. It may be because, under the current act, it may not be. That then is a good change, if we've blocked that hole, because we're all concerned about that kind of thing happening and I don't think it was the intent. We've just had a really good example of how there are some real changes that are acting together to solve some of the concerns people have raised.

**The Vice-Chair:** Do we want to ask ministry staff some questions? Okay. Could we have you sit at the witness table, and we'll start with Ms Boyd.

**Mrs Boyd:** I had a question on the last presentation, and it was something I hadn't really noticed before. It is in the Health Care Consent Act, paragraph 19(1)2. It is the underlined portion that Dr Velamoor gave: "if it is impossible to comply with the wish."

Could I have an indication from the ministry staff as to, first of all, what that would mean. I just need an indication of the circumstances under which that would happen, because Dr Velamoor goes on to say that would be a really impossible decision for a family to make. I don't think that was your intention, that that constitute impossibility. Impossibility might be something like somebody's up at the top of a tower and you can't get to them or something.

**Mrs Johns:** The treatment isn't available.

**Ms Auksi:** Yes. Partly, that's intended to address something which doesn't technically get into the scheme of the Consent to Treatment Act at all. If someone wants a treatment but it's not considered, let's say, clinically appropriate for them, it's to really make it clear that just because someone has wishes about treatment doesn't necessarily mean that treatment is going to be offered to them. That needs to be considered in the consent process, sometimes, by a substitute decision-maker.

**Mrs Caplan:** I have several questions. The first one relates to the last presentation about the removal of the section on the closeness of family. I just wondered what the rationale was for the removal of that section. If it was a political decision, fine, but I just wondered if that had been recommended by the ministry.

**Ms Auksi:** There are certain problems with inserting any kind of really inviolable rules. The kinds of situations that can arise are, for example, let's say siblings grew up together and actually are quite close but they live in different cities, but an important health care decision comes up and that sibling is the closest relative. In some cases that might not be an appropriate person, but in another case it might be a perfectly appropriate person. With parents of adult children that may happen too. They may end up living in separate places, and not everyone maintains contact by phone—they might not be able to afford to—and writing letters is not really that common, but they may still have a very close bond. If the person enters the picture and wants to be the decision-maker and someone has concerns that they may not be appropriate, there are ways under the act for alternatives to be explored. It's not as though they have a right to make that decision without anybody having any way of looking for alternatives.

If you set the rule that you had to have had close contact with the person over a certain amount of time, maybe the alternative would be that you'd have to go to the PGT. Is it necessarily better for it to be a public official as opposed to someone maybe you were very close to growing up but just very recently you might not have had contact with?

**Mrs Caplan:** Perhaps there's another alternative in those rare situations. Rather than a formal process of the PGT, there might be some other referral to the Consent and Capacity Board.

**Ms Auksi:** That can always be done. The thing is, let's say there was a friend who was willing to play this role—first of all, if it were a partner, they wouldn't even have to take any separate steps, but if it's a friend who doesn't fall into the "partner" definition, the incapable person could apply or the friend could apply to the Consent and Capacity Board to be appointed representative to make the decision. Some people may be hesitant to do that, but it's a heck of a lot simpler to do than to make a guardianship application, for example. It sounds as though that step has been taken by a number of people and that people are being encouraged to do it where it's appropriate.

**Mrs Caplan:** I'm just concerned that the act is too loose.

**Ms Auksi:** With regard to family.

**Mrs Caplan:** The assumption that a long-lost nephew who appears on the scene would be considered ahead of a friend I think is an issue.

**Mrs Johns:** But you could always take it to the board and have them evaluate it. If you're unhappy with who gets the decision under section 18, you can go to the board.

**Mrs Caplan:** Can the practitioner take it to the board? What would be the procedure for getting to the board in that kind of situation? Who would make the application?  
1550

**Ms Auksi:** The application to the board is by either the person who is proposing to be the representative—

**Mrs Caplan:** So the friend could do that?

**Ms Auksi:** The friend could do that. Or the incapable person, if the incapable person expresses a preference for



someone to be the decision-maker, someone may need to give them a hand, but they could make the application directly.

**Mrs Caplan:** Good. Unless you're going in rotation—

**The Vice-Chair:** No one else is on the list so if anybody else has a question, raise your hand.

**Mrs Boyd:** Just in pursuit of this, because I think I'm getting a lot clearer in terms of what the intention was. If there are no friends or relatives and this long-lost person appears, and there's no requirement for any kind of a declaration at all, if the person is incapable and unable to do that, can anyone else ask the capacity review board to look at this?

**Ms Auksi:** How do you mean?

**Mrs Boyd:** A care provider? Could a care provider ask?

**Ms Auksi:** You mean to become the representative, no.

**Mrs Boyd:** Let me give you the example, and it's one I know of personally, where an older person has a care provider who has been in the home for a number of years. In that number of years, there has never been any familial contact. This person slips into a comatose state, becomes incapable. And all of a sudden, out of the blue, in blows an in-law, under this—yours; in ours at least it would've been a relative, a real relative, but it's an in-law who suddenly says, "I will take charge of this."

There's considerable property involved. Who tells the public guardian and trustee? Is the care provider able, in those circumstances, to say to the public guardian and trustee: "Look, this person has arrived to take this woman's stuff. She really wanted to leave it to the humane society, but this person is going to come in and deplete this estate under a power of attorney—under a guardianship kind of thing, when she doesn't even know him, and he hasn't had anything to do with this." What do we do?

**Mrs Johns:** You've just moved from health to—

**The Vice-Chair:** Ms Johns, excuse me, I don't want the interjections. If you want to make a comment, raise your hand, and I'll put you on the list.

**Mrs Boyd:** But I have, and that's our problem. We keep slipping from one to another.

**Mr Garry J. Guzzo (Ottawa-Rideau):** We're asking the questions to the staff.

**The Vice-Chair:** That's fine, but what I don't want is for parties to interject back and forth. Simply raise your hand, and I'll put you on the list and you can make your comments then.

**Mrs Boyd:** May I just then complicate it by saying, and also under the health care part of the act, suggest the withholding of nutrition and hydration, which we've also heard about.

**Ms Spinks:** If I could address that, I think you're asking two questions. One is a general one, when someone may be a guardian or may have some decision-making role or claim some role, and there are nefarious motives or there's potential harm, is there anything that can be done, and, yes, under the Substitute Decisions Act, the PGT is authorized to investigate a report of either a threat to financial or wellbeing—

**Mrs Boyd:** From anyone.

**Ms Spinks:** —or personal wellbeing, from anyone. One of the problems is getting that complaint to the PGT, which is why the regulation authorizing disclosure to our office needs to be built in, because people who want to report that issue have expressed difficulty. But we could deal with that situation.

The second question I think is more specific. What do you do when someone claims, under the Health Care Consent Act, in the hierarchy, a right because "I'm an in-law" that maybe hasn't seen a person for five years, and they're saying, "I want to withhold treatment." And the practitioner's saying, "I think that this is because of a financial interest and this is actually going to do harm to the person," could we become involved? The answer would be yes. It will fall under the potential-harm-to-the-person category, and a guardian always takes precedence over somebody in the health care consent hierarchy.

**Ms Auksi:** Could I add to that too, the substitute decision-maker making a decision is not the only person who would be aware of that incapable person's condition, because if the substitute refused treatment that was clearly in the best interests of the person, then the substitute decision-maker can, in an emergency, treat notwithstanding, unless there were prior wishes to refuse that treatment by the person. On a best-interests basis, if they feel the substitute decision-maker was not complying with best interests, they can treat regardless, and if it's not an emergency, the health practitioner can launch a compliance review with the Consent and Capacity Board to question that decision, and the board then can give direction to that substitute as to how they should decide, and if they refuse to decide in that way, then they lose the right to make the decision. If they don't act properly, there are ways to address that.

**Mrs Boyd:** In one of our presentations, one of the presenters suggested, is there some way that we can have some kind of a flow chart that really shows how all of these things work together, for the family physician, for the psychiatrist and the emergency department, for the home care provider, for relatives? Is there some way we can flow this so we can see how these things interact, so that it's easily seen?

I think it would alleviate some of the real fear, real panic that we've heard from people, and I think we need to respond to. If people knew how this was—and knew that was going to be generally available. We've heard a lot of talk about the need for education, but clearly, when we start to talk about it, we skip from one act to another, and get confused, and we've got the thing in front of us and we've been really working hard at this. I think when people come before us and say this is still very complex, even though it's simplified, that one of the jobs we need to be trying to do as we go on is find some way to get that reassurance by showing how this all works together.

It really needs somebody who thinks in graphic terms, which I don't but I know some people do, and it might help us to explain what's going on.

**The Vice-Chair:** Thank you, Mrs Boyd. I want to move on now. We've got our next presenter here, and I want to thank you for your information.

## CHILDREN'S HOSPITAL OF WESTERN ONTARIO

**The Vice-Chair:** The next presenter will be Dr Sandra Fisman from the Children's Hospital of Western Ontario. You've got 20 minutes, and you may want to leave some time for questions at the end, and you can begin any time.

**Dr Sandra Fisman:** I'm very happy to be here because it isn't often that child and adolescent psychiatry gets a chance to input into some important changes, and these are important changes. So thank you.

I wanted to let you know that the current legislation has created many dilemmas for us. It's been somewhat of a nightmare, particularly in caring for 14- and 15-year-olds, and what we've found is that the needs and the rights of kids, of adolescents, have sort of been pitted against their parents, and it's been very difficult at times.

There's also been a spillover. I heard something about different legislative issues, and how they spill over from the consent and other acts, and one of the things that's happened to us is that there's been confusion at the moment as to whether kids who are able to consent can then sign their own form 14s and release their own information. So it's been very difficult.

There have been difficulties where kids have consented to treatment and haven't wanted their parents to know about the treatment, and we've wondered about our legal liability in those cases. And there's been the reverse, where parents have wanted kids in treatment, kids who are competent to consent have refused, and that's created a nightmare as well.

While I think it's an oversimplification to have found a magic age where you think kids are capable to consent to treatment, nevertheless, I think we would support the fact that you've done that, and would see, given that there are going to be times where we'll feel that a kid of 14 is really quite competent to consent, weighing that versus the nightmares that we've experienced, that it'll be better to have a uniform age of consent.

We would ask, as a group, that you consider something beyond that, that for adolescents, the different legislation that deal with when they're allowed to do different things, just creates a nightmare in confusion. For example, you can smoke and drink at different ages. You become an adult criminal at a particular age. You can vote at a particular age. You can drive at a particular age, and none of the ages are congruent, or most of them aren't. What I think would be a solution, and the people I work with agree with me, is that if we had a uniform age of majority, adolescents would be a lot less confused, and one of the logical ages may be to pick 18 as the age of majority. So I would suggest that to you as something to think about. I know it's complex and it goes beyond the changes that you're suggesting.

1600

The second area that I would support is the changes in the definition of treatment. I think it's been difficult for us to define some of the things that we do as risk treatment, so family therapy, milieu therapy, individual therapy, are low-risk, no-risk kinds of treatments, and it'll be very nice not to have to worry, if you like, about

consents for each of those treatments, that we can have a therapeutic alliance and work with people, but not get into the issues that we need to get into with the designated treatment.

We would support that change as well, and we would also support the change where one can make minor modifications without a new consent, and that seems to make a lot of sense to us as well.

The other thing I would like to support is that you have clarified for us the ranking of a custodial versus an access parent, and that's very helpful. It's been most unhelpful to have to have the consent of two separated parents, where one parent is a custodial parent and the other parent is an access parent, and to have to go to the public guardian to decide on an issue where an access parent disagrees with a custodial parent, where the custodial parent was in fact given the right by the courts to have custody of their child. So clarifying that has been very helpful.

The other area that I think is going to be helpful for us that again we would support—and you must be wondering why I'm supporting everything that you're suggesting, but they're very helpful changes—is the whole issue of the informal patient, between the age of 12 and 15. It's going to be very helpful that a kid between the age of 12 and 15 not be able to apply to the Consent and Capacity Board to review the decision that's been made by their parents for them to be in treatment.

The only concern I have is that you haven't clarified for us whether the Mental Health Act will supersede that or whether this will supersede the Mental Health Act. So under section 13 of the Mental Health Act, in fact children at that age, as informal patients, have the right to a review board, as it's stated in the Mental Health Act. And unless you clarify that for us in this act, it's going to be very confusing.

The other thing I haven't mentioned in the handout that I've given you is that there is a statement that the Child and Family Services Act will supersede this act and all acts, and that makes a lot of sense, because child protection issues need to be dealt with first, and then the treatment issues become much more simple when there is an appropriate legal guardian.

In summary, we really support the changes, find them very helpful and would only suggest that you look at a uniform age of majority that would cross all legislative issues for children and adolescents.

**The Vice-Chair:** We've got about 15 minutes left for questions, five minutes per caucus, and we'll start with the Liberal caucus.

**Mrs Caplan:** I'll keep it brief because my colleague has a few other questions also. It's my understanding that the Child and Family Services Act, children's mental health and all of that under Comsoc is dealt with and then the Mental Health Act here, so you have a continuum. Frankly, from my experience as a former Minister of Health, I felt that worked reasonably well.

The intent of the Health Care Consent Act, which I also support, leaves silent and allows the health practitioner to determine whether or not the child is at an age where they can appreciate what a treatment is, and the difference here is that when you're dealing with mental



illness or mental disability or even physical disability that may impact on capacity from time to time, the difference here is that access to the health system for other types of services are a singular event, and may result in treatment for that purpose.

We heard from Sick Children's Hospital, for example, that children who are suffering from a sexually transmitted disease will not talk to their parents, will not even go to their family doctor, but will want the anonymity of the big hospital and present there. We know that whether it's in young men or young women, untreated sexually transmitted disease can lead to terrible damage if left untreated. I'm not sure your concerns are not addressed by existing legislation. In fact, I'm comfortable that when it comes to age, there's no one consistent number that we should apply to all legislation. I'm going to leave Mr Ramsay—I don't have a question. I just wanted to give you my perspective on that. If you disagree, we'll just disagree on it.

**Mr Ramsay:** Do you have a response to that first?

**Dr Fisman:** Yes, and I appreciate what you're saying. You have to look at both sides of the story. One of the good examples that I could give you would be of a young adolescent with an eating disorder who clearly needs treatment, who will generally not see the need for treatment but who has parents who are adamant that their kid needs treatment, and that kid may be competent to make a decision about treatment. He may not be at a level of physical danger where you could say that he needed emergency treatment.

**Mrs Caplan:** Under this act, you should be able to treat him if you deem the child competent enough to make the decision.

**The Vice-Chair:** Mrs Caplan, Mr Ramsay has the floor. His mike is the one that's on.

**Mr Ramsay:** Thank you very much, Mr Chair. That's great.

**Dr Fisman:** I wondered if I could just finish the problem. Under the existing legislation it becomes very difficult, so you would say to that 14-year-old, "You need to be in treatment," and the 14-year-old would say: "I don't need to be in treatment. My parents think I need treatment but I don't." You would then have to judge them incompetent, get them a legal rights adviser and their parents would then be pitted against the legal rights adviser, who may say, "Well, you have every right to decide whether you're going to be treated or not."

**Mrs Caplan:** Or go to the board.

**Dr Fisman:** What happens is, the kid goes untreated.

**Mrs Caplan:** Or goes to the board, and the board decides the kid's incapable and then you get to treat.

**Dr Fisman:** It's difficult.

**The Vice-Chair:** We're going to move on now to the NDP caucus. Five minutes has expired.

**Mr Clement:** I just want to say for the record I agree with Elinor.

**Mrs Caplan:** It is only because it's Valentine's Day.

**Mrs Boyd:** That was worth getting on the record, Mr Chair.

**Mr Ramsay:** You're wearing them down, Elinor.

**Mrs Boyd:** Dr Fisman, I want you first of all to know that I really admire the work that you've done. I know

that you are greatly thought of in our community, so I would not want you to think that anything I'm saying is a criticism of your personal work, because it certainly isn't.

**Dr Fisman:** Thank you.

**Mrs Boyd:** This act does not give 16 as the age of consent. I may be reading your paper wrong, but you seem to be assuming that it does. In fact, you should know that all three parties here are in agreement with the act as it stands, that there be a presumption of capability regardless of age. You need to know that we hear you, we don't happen to agree with you, but we really have looked at all of these ramifications. It's not that we haven't looked at them. We've all struggled with them now for a lot of years and it's a very difficult issue.

**Dr Fisman:** It's difficult, then, to interpret the act because it repeatedly comes back to "and if this person is 16 years or over, then...." So the assumption is that under 16 there would be a different set of rules.

**Mrs Boyd:** I believe that's only in the Substitute Decisions Act. I may be wrong about that, but I think in the Substitute Decisions Act we don't allow someone to substitute their decision for an incapable person until they're 16. I believe that's the only place 16 is mentioned.

**Mrs Caplan:** It's for the purpose of a power of attorney.

**Mrs Boyd:** It's for the purposes of a power of attorney.

**Dr Fisman:** Okay, so it's not in consent to treatment.

**Mrs Boyd:** It's not there.

**Dr Fisman:** Thank you for pointing that out.

**Mrs Caplan:** Consent to treatment signed—

**Mrs Boyd:** My second issue: You made a comment, in terms of treatment, allowing little no-risk treatment. I know you do a lot of work with anorexics, I have reason to know how difficult that is, as a parent, and I understand entirely what your concern is.

In that situation of an anorexic child refusing to eat, under 90 pounds, what would you consider a no-risk treatment?

**Dr Fisman:** Under 90 pounds? Well, you know it depends on whether the 90 pounds is a critical weight for that particular kid.

**Mrs Boyd:** Yes, let's assume it is.

**Dr Fisman:** That then becomes an emergency so that isn't an issue.

**Mrs Boyd:** All right. So if we take that same kid, same body build and have it at 110—

**Dr Fisman:** Then it's a different story.

**Mrs Boyd:** Okay, and what would be a no-risk treatment?

**Dr Fisman:** A low-risk treatment would be individual work, family work and working with the nutritionist. That is a low-risk but beneficial treatment.

**Mrs Boyd:** Okay, so when you talk about low-risk, you're really talking about very non-intrusive, low-risk treatments that are encouraging and supportive of the person but not in any way like force-feeding or that sort of thing?

**Dr Fisman:** That's right. That's not a no-risk—

**Mrs Boyd:** I just wanted to clarify that because I think sometimes we get a different nuance, from physicians who come forward, in terms of the continuation of treatment or some alteration in treatment that gives pause to us in terms of whether it is really little or no risk. I just wanted to ascertain that was clear.

**Dr Fisman:** Yes, and it really comes down to the intrusiveness of the treatment.

**The Vice-Chair:** Mrs Caplan, we're going to move to the government side now. The five minutes have expired.

**Mrs Boyd:** I'm Mrs Boyd.

**The Vice-Chair:** Oh, Mrs Boyd.

**Mrs Caplan:** I'm Mrs Caplan.

**The Vice-Chair:** I know who you are.

**Mrs Boyd:** We may look exactly alike, but—

**Dr Fisman:** And I'm Fisman.

**The Vice-Chair:** Thank you, Mr Clement.

**Mr Parker:** Maybe we just can't tell the Liberals and the NDP apart. That's our problem.

**Mr Clement:** Just getting serious for at least half a second here, I have been personally grappling with this age-of-consent issue, because in the case of good parents who care about their child—and I know we can get into an argument about what is a good parent, bad parent—I don't want to be putting impediments in the way. Anorexia nervosa is a very cogent point on this. I guess I have a bit of confidence that in the case of good parents and good health practitioners both agreeing that a course of treatment is necessary, and in the case of the child disagreeing with that course of treatment, our system has enough in it under this legislation to allow the parents and the health practitioners to basically have their way. If that isn't the case, if that isn't what occurs, then I would like to revisit this legislation. But I think that's the only way we can grapple with the situation and balance that off with the case where we have kids who don't have parents or who have bad parents and we need a way to deal with them as individuals and allow the treatment to take place. So I just wanted to say that.

**Dr Fisman:** It sounds to me as though my misreading of the act and your clarification still mean that a 14-year-old who is not competent to consent will not have to go to the Consent and Capacity Board; the parents will then consent, which is fine.

1610

**Mrs Boyd:** That's right.

**Mr Clement:** In the first instance. They have the right to appeal, but in the first instance, you're right.

**Dr Fisman:** That would then solve the whole issue of the adolescent with a sexually transmitted disease who doesn't want parents to know about treatment. It doesn't solve our dilemma of treating somebody where there is some risk and not letting the parents know, the treatment

going wrong and then deciding who is liable. That's a dilemma for us.

**Mr Clement:** That is an extraneous issue.

**Dr Fisman:** It's not an extraneous issue if you're a practitioner.

**Mr Clement:** No, but I think what I described was a risk situation.

**Mrs Boyd:** An ectopic pregnancy, you could treat.

**Mr Clement:** That's right.

**Dr Fisman:** Just an emergency situation.

**Mrs Boyd:** No, even without it, if the child agrees, you treat.

**Mr Clement:** Emergency situation, go right ahead.

**The Vice-Chair:** Ms Boyd, sorry.

**Mr Clement:** Emergency situation, go right ahead. No-risk situation, go right ahead. It's a risk situation, where there are costs and benefits of a course of treatment, where we get into this. That's what we're talking about.

**Dr Fisman:** May I ask a quick question, then? A competent 14-year-old who wants to go on the birth control pill and doesn't want parents to know can go on to the birth control pill. You don't need to let the parents know. The kid has a thrombosis, and who's liable?

**Mr Clement:** I'll take door number 2 for \$500. I don't know the answer to that.

**Mrs Boyd:** I suppose with the Health Care Consent Act you should be fine.

**Mrs Johns:** Yes. I was going to say that as long as the child, when they're making the decision, is able to understand the decision and is able to appreciate the reasonable effects that could cause, then the health care practitioner is not liable. So the child who decides to take birth control is capable, therefore, understands—

**Mrs Caplan:** I agree with Helen.

**Mrs Johns:** Thank you. Thank you very much. If you've explained that that is a potential that could happen, then the health care practitioner is not liable.

With respect to section 4—you ask if you need clarification—your assumption is correct. The revised act states that an informal patient between the ages of 12 and 15 may not apply to the Consent and Capacity Board for review of a decision to consent, on the person's behalf, to their admission to a psychiatric facility—clarification as to whether this is superseded by the right of application for informal patients between the ages of 12 and 15 under section 13 of the Mental Health Act. That is correct.

**The Vice-Chair:** We are out of time. Dr Fisman, I want to thank you very much for your presentation.

We will stand adjourned until tomorrow morning, Windsor, at 9:30.

*The committee adjourned at 1616.*









## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

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**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

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Chiarelli, Robert (Ottawa West / -Ouest L)

Conway, Sean G. (Renfrew North / -Nord L)

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\*Ramsay, David (Timiskaming L)

Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

**Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Orléans L) for Mr Conway

Clement, Tony (Brampton South / -Sud PC) for Mr Tilson

Duncan, Dwight (Windsor-Walkerville L) for Mr Chiarelli

Johns, Helen (Huron PC) for Mr Hudak

Marchese, Rosario (Fort York ND) for Mr Hampton

**Also taking part / Autres participants et participantes:**

Wood, Bob (London South / -Sud PC)

Ministry of the Attorney General

Spinks, Trudy, manager, implementation support and counsel, implementation support unit

Ministry of Health

Auksi, Jutta, senior consultant, legislation policy unit

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service

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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Thursday 15 February 1996

# Journal des débats (Hansard)

Jeudi 15 février 1996



## Standing committee on administration of justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

## Comité permanent de l'administration de la justice

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Thursday 15 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Jeudi 15 février 1996

*The committee met at 0930 in the Ramada Inn, Windsor.*

ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

## LEGAL ASSISTANCE OF WINDSOR

**The Chair (Mr Gerry Martiniuk):** Good morning. This is the continuation of the standing committee on administration of justice hearing on Advocacy, Consent and Substitute Decisions Statute Law Amendment Act, Bill 19.

The first submission we have this morning is Legal Assistance of Windsor, Ms Rose Voyvodic, executive director. Welcome. You have one half-hour, which you can use as you see fit. That includes questions, however, and I'll cut you off at the end of the half-hour. Proceed.

**Ms Rose Voyvodic:** Good morning. Legal Assistance of Windsor, which was founded in 1974, is a community legal clinic sponsored by the faculty of law at the University of Windsor and funded by the Ontario legal aid plan. Our reason for asking to appear before your committee today stems from an ongoing interest in the topics of advocacy, consent to treatment and substitute decision-making. Legal Assistance of Windsor, or LAW, as it's known locally, provides legal and social work services to low-income members of the communities of Windsor and Essex county, many of whom are described currently as vulnerable in the Advocacy Act. We also provide public legal education in the community, based upon demand and need. In the last two years, for example, LAW staff engaged in numerous workshops and presentations to various individuals, groups and agencies, largely stemming from community interest in the development of this legislation.

We have many serious concerns with the bill before your committee. Our submissions, however, only address

the repeal of the Advocacy Act and the amendments to the Substitute Decisions Act. We thank you for the opportunity to comment on this legislation and trust that the comments of our agency, together with the presentations you'll be hearing from local organizations, will be considered in your deliberations.

First, I'd like to speak to the repeal of the Advocacy Act, which in our submission is the most significant change brought about by Bill 19. This act, which is barely one year old, as you know, aimed to provide advocates to vulnerable people who required assistance in asserting their rights. Additionally, advocates empowered under this legislation had other powers derived from the Substitute Decisions Act and the Consent to Treatment Act in the sense that they acted as rights advisers. In cases where persons alleged to be incapable were to be deprived of decision-making powers regarding their person or property, there was a function for advocates under those pieces of legislation. All these concepts—that of the advocate, rights advice and rights adviser—in our submission are fundamental to protection of Ontario's most vulnerable members of society, and all these concepts are abolished under Bill 19.

Our understanding from the communiqué of the Ontario Ministry of the Attorney General from November 15 of last year is that the government views the Advocacy Commission as an intrusive and bureaucratic government agency. In our submission, the intrusive qualities of the system exist only to assist those vulnerable persons who may be incapable of defending against potentially enormous intrusions, such as court-ordered guardianship, and arrest and detention for purposes of court-ordered assessment, without the minimal protection of rights advice.

We question whether it is necessary to repeal this legislation without substituting a less intrusive, effective alternative system of advocacy to provide rights advice to persons about to be deprived of the right to make important life decisions about their person or property because of an alleged incapacity. We are particularly concerned that this system of advocacy is being removed at a time when demand for services to existing organizations is high and the future of organizations such as community legal clinics is uncertain.

With respect to rights advice, there are numerous functions of the advocate under the Substitute Decisions Act, including but not limited to notifying and explaining to a person the certificate of incapacity and the legal rights surrounding this step, and explaining the significance of court-ordered guardianship and one's right to oppose the application for same. All these functions of the advocate are abolished under Bill 19.

Other examples of rights advice contemplated under the Substitute Decisions Act which are also abolished include notifying a person that a notice of termination of statutory guardianship has been issued; meeting with the person subject to the hearing of an application to court for temporary guardianship; notifying a person that a temporary guardianship order has been made without notice, and explaining the effect of the order and the right to apply to court to terminate the guardianship; meeting with a person alleged to be incapable where a restraining order is sought to assist in implementing a court-ordered assessment; and meeting with a person alleged to be incapable where an order for arrest and detention to provide a court-ordered assessment is made.

Please note that even though the opportunity to receive rights advice in these circumstances has been removed, there is no corresponding amendment made by Bill 19 with respect to the powers that were given to the Ontario Court (General Division) to make various orders relating to financial or personal guardianship, and also relating to arrest and detention, even where a person has not yet been found to be incapable of managing his or her affairs.

We question the fairness of a system where a person is not given information by a rights adviser required to assist the person to understand the issues affecting him or her, and enabling him or her to seek advice, legal advice if necessary, and to assert his or her rights before an order is made.

The rights information system created by Bill 19 in our submission applies only in very limited circumstances. These are basically related to informing a person that the public guardian and trustee has become the statutory guardian and that a person has a right to appeal; also, informing a person that an application for court-appointed guardianship of property or the person has been made.

It is not appropriate that rights information be given by the parties seeking to be guardians or the office of the public guardian and trustee. The availability of independent rights advisers, who will meet in person with the vulnerable person, would ensure that rights advice is being properly delivered.

We agree with the submission already made to you by the Advocacy Centre for the Elderly that a duty counsel system could be arranged where rights advisers are paid on a fee-for-service basis. That would restrict the cost of the service without restricting access to advice and access to justice.

I'd like to also address the issue of who may be witnesses to powers of attorney under Bill 19. We are aware that Bill 19 has not removed the provisions relating to powers of attorney for personal care and property, which we view as beneficial improvements created under the existing legislation to the legal regime governing incapability and incapacity.

However, we are extremely concerned that the prohibition against children of the grantor of a power of attorney, even where those children stand to benefit financially from the transaction, acting as witnesses has been removed. In our submission, this provides and creates opportunities for exploitation and even abuse by children wishing to gain control over a vulnerable parent's estate.

There appears to be no sound reason to remove this prohibition, and in fact we can see no basis for it when it is common sense and very well established in law that a beneficiary under a will, for example, may not be a witness for the very purpose of preventing abuse. We are concerned that serious potential for harm is created by the removal of this prohibition.

There is also, relating to witnesses to powers of attorney, language in Bill 19 repealing sections of the Substitute Decisions Act which require witnesses to signify that they have no reason to believe that the person signing the power of attorney is incapable of giving a continuing power of attorney for property or a power of attorney for personal care. We do not understand the basis for this change and are concerned that this check on potential abuse is removed. The minimal requirement that a witness indicate that there is no reason to believe incapability is present would seem to provide some protection against an incapable person signing such a document.

#### 0940

With respect to who the suitable guardians of the property and of the person are, we are concerned about some of the themes running through Bill 19 which relate to the role of the public guardian and trustee, and also with respect to the role of paid service providers. Currently under the legislation, service providers are prohibited from being appointed as an incapable person's guardian of property or the person, unless that caregiver is the incapable person's spouse, partner, relative, guardian of the person, attorney for personal care or attorney under a continuing power of attorney. While this prohibition continues generally, Bill 19 does allow for persons who provide care or residential social training or support services for compensation being appointed, and not the public guardian and trustee, where there is no other suitable person who is available and willing to be appointed.

Again, there are many serious potentials for abuse created by these amendments. How can a paid service provider order and receive payment for additional services for a person under their guardianship without being in a conflict of interest? The concept of "fiduciary" would seem to apply in these situations, as it would in common law. The potential that a vulnerable person has for challenging any decisions after they are made is extremely limited. It would seem to make more sense to prevent the abuse or prevent the potential for abuse rather than provide for an opportunity to redress them later.

While we agree that the public guardian and trustee should only be appointed as a last resort, we would argue that it is extremely inappropriate for paid service providers to be appointed. We urge the committee to evaluate a more appropriate solution to this problem, which we would suggest would be to continue to enable an independent body, such as the public guardian and trustee, to act as a substitute decision-maker for people who have no other suitable, willing person to act for them. The paid service provider would then take direction from the substitute decision-maker rather than playing both roles.

With respect to the power of attorney for personal care, this creature of the existing legislation—which is continuing, we're pleased to say—was long awaited and much



needed in this province. However, we view the changes under Bill 19 to the validation and confirmation process which trigger the exercise of this power as potentially dangerous.

The current system puts in place certain protections against abuse of the power of attorney for personal care. Currently, in order for an attorney to exercise power upon a person becoming incapable, that attorney must submit two assessments proving incapacity and a guardianship plan. The public guardian and trustee is also used as a substitute for the court in confirming that the attorney may now exercise the power. Under Bill 19, the attorney may exercise authority under the power as soon as he or she has reasonable grounds to believe that the grantor is incapable. There is no requirement that the attorney inform the grantor that he or she is now acting as substitute decision-maker unless a grantor has written that requirement into the power of attorney for personal care, which would require some foresight on the grantor's part. Thus, a grantor may be unaware that personal decisions are being made on his or her behalf in order to take the necessary steps to revoke the power given.

It is necessary, in our submission, to amend the Substitute Decisions Act to require that notice be given by an attorney to the grantor that the attorney believes the grantor is incapable of making personal care decisions and that the attorney is acting on the grantor's behalf under the authority of the power of attorney for personal care.

With respect to potential access to confidential information being provided to third parties, Bill 19 provides that regulations may be made permitting access to this information by applicants for guardianship, which is a category, in my submission, which could include anybody. However, no duty to maintain confidentiality is attached to this right of access.

There's also a power given in Bill 19 to create regulations addressing the right of assessors acquiring relevant confidential information, and while we understand that may be necessary in order for an assessor to complete a capacity assessment, we are concerned that access to this information is, it would seem, going to be provided without authorization from either the person concerned, his or her attorney, a court or someone authorized under the Mental Health Act.

Again, on the subject of the role of the public guardian and trustee, in Bill 19 there's a repeal of the current sections of the Substitute Decisions Act which provide for the public guardian and trustee to act as a substitute where a statutory guardian ceases to act or where it is necessary to prevent harm.

The amendments under Bill 19 provide for the substitution of the public guardian or trustee in this regard on a temporary basis if the public guardian or trustee elects to do so, where a statutory guardian dies, becomes incapable or resigns. There is no requirement that the public guardian or trustee so act and there is no requirement that the public guardian or trustee act to prevent harm. This, in our submission, creates a void which needs to be filled.

Under the current Substitute Decisions Act, the public guardian and trustee may apply to a court for temporary

guardianship of the person and receive an order for 90 days where notice to the person concerned is provided, but only for seven days in urgent situations, where no notice is given to the person concerned.

Under Bill 19, there is the possibility of a 90-day order without notice being created. In our view, this is an unreasonably long time for a person to be deprived of the right to make decisions for himself or herself and appears to have no corollary or analogous time period elsewhere. Under family legislation, under the rules of court relating to injunctions, for example, the time period is much shorter, and we would suggest that a maximum of 30 days or some reasonable alternative between seven and 30 days be struck to use in that situation where it is an urgent situation.

The use of confinement, restraints and monitoring devices is also addressed under Bill 19 in that it removes the section of the Substitute Decisions Act requiring that a guardian set forth in the guardianship plan an indication that restraints, confinement or monitoring devices may be used on an incapable person. The current requirement is that restraints should not be used unless it gives the incapable person greater freedom or to prevent serious harm, and that requirement continues. However, all guardians would have the power to consent to the use of restraints whether or not they were ever contemplated by the guardianship plan. In our view, that could lead to some abuse, whether intentional or unintentional.

The use of electroconvulsive treatment is currently prohibited in the form where it may be used as aversive conditioning under the Substitute Decisions Act. Bill 19 removes this prohibition and does not appear to set forth any control mechanism such as a requirement that a court order be obtained to guard against the potential for abuse.

Finally, the so-called Ulysses agreements under the power of attorney for personal care, which under the former legislation could be tailor-made, so to speak, to suit the needs or wishes of the person granting this power, have been removed under Bill 19 and a standardized agreement to intervention is created.

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We understand that there may be a practical reason for standardized agreements being used, in the sense that they may be documents more easily used by health care practitioners etc, but we're concerned that there is no measure of input, at least with respect to what the grantor can state in this power of attorney for personal care. It's also set out in a prescribed form, and that sets out the circumstances in which force may be used and the right to use force. Because of the standardized nature of the prescribed form, it appears that these powers may not be deviated from.

Also, with respect to the so-called Ulysses agreement, there is no requirement in Bill 19 that a guardianship plan be filed or that rights advice be given. The power comes into effect when the attorney believes that the person is not capable. Again, there is that extreme potential for a person not being aware of what is happening. Once again, it is urged that some system of advice be provided, on a fee-for-service basis, prior to an agreement carrying such serious potential repercussions being signed.



In conclusion, we are making these comments today to this committee recognizing the tremendous effort which was put into enacting the legislation under amendment as well as the concerns raised by health care practitioners and service providers. We urge the committee to bear in mind the level of consultation undertaken in the prior process. Many vulnerable people put countless hours of thought and deliberation into grappling with the complex balancing of interests required in enacting legislation which protects rights while at the same time providing for the orderly administration of society.

We would also like to add that while we have not chosen to comment on the amendments created by the Health Care Consent Act, we share the concerns already made to you and put forward in the submission of the Advocacy Centre for the Elderly and its submission to this committee on February 7 in Toronto. Thank you.

**Mr Rosario Marchese (Fort York):** Thank you, Ms Voyvodic, for your submission.

**Ms Voyvodic:** You're welcome, Mr Marchese.

**Mr Marchese:** See how we relate to each other so well.

I found your presentation very thoughtful and I want to say that a number of the submissions you've made have been raised by quite a number of different groups, and you seem to share the same concerns. You make a number of useful points and suggestions as to how we might solve some cases of problems. One of the points you make here at the end is, "Again, it is urged that some system of advice be provided, on a fee-for-service basis, prior to an agreement carrying such serious potential repercussions being signed."

The point you make here is, how do we balance "interests required in enacting legislation which protects rights while at the same time providing for the orderly administration of society"? Because that's what the government seems to be interested in, how do we facilitate making sure that people get the care they need quickly? We understand that and we all agree with that. At the same time, our objection on this side is that for the most part we think people need to have greater protection and need to have those rights being given by somebody. The point of it is, once you've eliminated the Advocacy Act and the rights advisers, you eliminate an important tool.

Now the government says this is institutionalized advocacy, it's not good. We should find other forms to give that kind of advocacy. We think you can't find another form and that these people need that authority to be able to intervene. Your fee-for-service might be able to do it. I think something needs to be put in place if they eliminate that, but I'm not quite sure whether we've convinced the government members that that needs to be put into place.

**The Chair:** Mr Klees.

**Mr Frank Klees (York-Mackenzie):** I'll defer to Mr Parker.

**Mr John L. Parker (York East):** Thank you very much for your comments. There are a number of points I'd just like to respond to. First, you made the point that, in your view, the government took the view that the existing legislation was intrusive so the government was

taking these steps. I want to assure you that the government didn't just cook this up on its own. We have received literally thousands of telephone calls and thousands of letters; 80,000 phone calls to the public guardian's office and 40,000 letters making the same point, that they find this intrusive. Many newspaper articles have made the same point. The Windsor Star this week endorsed the changes we're making on the same basis.

Let me just respond to a few of the other points. In point 3 you indicate some concern about the removal of a prohibition against children signing as a witness to a power of attorney, that it creates a conflict of interest because it creates the possibility that someone would benefit. There is still a prohibition against the attorney, the one receiving the power, acting as a witness. That is still in the statute. The common-law rules of conflict of interest still apply besides. So that hasn't changed under the proposed bill.

You make the point in point 7 that the guardian doesn't have to explain to the person who is under guardianship what is being done. I want to refer you to section 66 of the existing act, not the bill but the existing act, which addresses that point dead on. I won't go through it with you, but section 66 coupled with section 68 of the existing act—and these sections are not being changed in this respect—covers off that particular point.

**Ms Voyvodic:** In my point 7 with respect to preventing harm? Which? Sorry.

**Mr Parker:** That the guardian need not explain to the incompetent person that the guardian has taken over and will be making decisions; that point is addressed in the existing legislation and is not being amended.

**Mr Dwight Duncan (Windsor-Walkerville):** You made a number of submissions, particularly with respect to the Substitute Decisions Act. One of the themes that seems to be underlying the amendments both to the Substitute Decisions Act and the Consent to Treatment Act is the notion that family members and care providers can be entrusted. Virtually all of the proposals you've put forward put conditions or restrictions on this. Your submission is very clear, and we've heard this before.

My question to you relates to your practice and your experience in your practice in these situations. Can you share with us an overview of the kinds of situations you've observed where in fact families or other trustees or guardians aren't in fact necessarily acting in the best interests of a vulnerable person or somebody who has had to give up the power to make decisions.

**Ms Voyvodic:** I think examples of these situations have been really well documented, numerous submissions made when the advocacy legislation was being contemplated. The report of Dr Lightman with respect to a different piece of legislation relating to residential care homes documented the existence of some issues right here in Windsor with respect to nursing care homes.

I think the philosophy or the ideology that is visible in either piece of legislation is clear. On the one hand, as you are saying, there is a notion that trust may be extended to these members of the family or members of the community. On the other hand, there is a view that, while in the best of all possible worlds that is something



to be fervently hoped for and wished, there is a reality where that is not always the case.

In striking a balance and providing for the kinds of concerns that are expressed with respect to intrusiveness or with respect to bureaucracy even and numbers of forms to be filed etc., it seems like there must be some way of striking a balance while recognizing that a society can be valued or recognized—and I'm going to mangle the quote from Winston Churchill or Socrates, whoever said that it's how you treat your disadvantaged or your vulnerable people while at the same time recognizing that there is a need to not only protect the rights of these vulnerable people but also to protect them from abuse.

**The Chair:** Thank you very much for your submission.

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#### WINDSOR ESSEX COMMUNITY ADVOCACY NETWORK FOR PERSONS WITH PHYSICAL DISABILITIES

**The Chair:** Our next submission is the Windsor Essex Community Advocacy Network for Persons with Physical Disabilities. Dean La Bute is the chairman. We have one half-hour allocated for your submission, and you can use it as you see fit. You may proceed.

**Mr Dean La Bute:** Good morning, Mr Chairman and members of the standing committee on administration of justice. My name is Dean La Bute, and I'm chair of the WECAN organization.

Before I get into my presentation, I would like to challenge the members of this committee to spend a few minutes in the shoes of a disabled person. What I have brought with me today are 16 pairs of special glasses from the Canadian National Institute for the Blind which simulate different eye conditions, so that you may have a taste of what more than 38,000 Ontarians experience every day of their lives. I would very much like the members of this committee to have the opportunity to experience this for a few minutes. Your cooperation in this matter would be most appreciated, Mr Chairman, you and your committee members.

**The Chair:** A fine suggestion. We will try to experiment with those.

**Mr La Bute:** All right. I would ask that you try to read something. I ask that you try to write your name on a piece of paper. You will see the unique experience that you will experience. I will also bring to your attention that throughout my presentation I ask that you leave the glasses on for periods of no longer than five minutes, otherwise it will have an adverse effect upon the breakfast you had this morning, and you'd rather not experience that, I'm quite certain.

As those are being circulated to you, ladies and gentlemen, I want to address the issue of why my organization is here today, once again appearing before this committee, and why this time we are withholding our written brief to you. I think a Latin phrase most eloquently addresses the issue: *Quid pro quo*. When the government of the day provides to the more than 38,000 blind and visually impaired Ontarians copies of your bills in a format that's accessible to us, be it in print, Braille or on

tape, we in turn will comply with your request and submit to you our written submission pertaining to Bill 19. So today I will speak to that issue.

The Windsor Essex Community Advocacy Network is a grass-roots, non-profit, non-government organization. It is comprised of physically disabled individuals from Windsor and Essex county and approximately 30 organizations that provide services to the physically disabled. I, for example, represent on this organization the Canadian National Institute for the Blind. Other member organizations, for the sake of informing you, are the Victorian Order of Nurses, the Canadian Hearing Society and many other such organizations, which are voting members. It is worth noting and informing you that the majority on the council are consumers, physically disabled individuals.

We also have as members of our organization resource representatives, and we have sitting as resource people but non-voting members representation from the hospitals, the boards of education, the Ministry of Health, the Ministry of Community and Social Services and the city of Windsor social services department. As you can tell, we are an organization that broadly represents the disabled community and those who provide services to the physically disabled.

When the advocacy legislation was first brought forward by the then NDP government, we appeared before this committee at that time and did in fact make a written submission to this standing committee. In that brief, which is a part of your Hansard record, we articulated our support for the Advocacy Act, the Consent to Treatment Act and the Substitute Decisions Act. Our position on that has not—and I stress has “not”—changed.

We feel that Bill 19 turns a blind eye and a deaf ear to the plight of vulnerable people in Ontario. The fact remains that it absolutely seems to sweep aside the Advocacy Act and the components of that act, because from the point of view of vulnerable people, and in particular the physically disabled, we looked upon December 10, 1992, as a day of reckoning in that through the proclamation of the Advocacy Act, vulnerable people in Ontario were given equal status, were provided with a level playing field with the rest of society.

For far too long, vulnerable persons have been marginalized, ignored and have been looking from the outside in and knocking at the door to become equal partners, have equal status within society at large. In our opinion, the Advocacy Act opened that door and allowed us in. Bill 19 throws us back to the dark ages with the repeal of the Advocacy Act.

Advocacy and the plight of the poor and the disabled and the vulnerable is not new in this century, was not first addressed by the NDP government or the Conservative government prior to that, but it goes back for centuries. The Dutch-Jewish philosopher Benedict Spinoza, well-noted in the 1700s, a student of Descartes, clearly articulated to the authority of the day that it was not within the ability of individuals or groups of individuals to provide proper care and assistance to the poor and those in need of help, but rather it was incumbent upon society as a whole. Today, the mechanism in society that

has the means, the ability, the resources to coordinate and provide that safety net is the government of the day.

I ask that you keep in mind that the Conservative government under Mr Bill Davis commissioned a report that in fact did address this issue, the Fram report. The following Liberal government under Mr Peterson also commissioned a report, the O'Sullivan report, and that once again clearly identified and brought forward viable means of addressing the issue of the plight of vulnerable persons in Ontario. Then the NDP government finally acted upon these successive reports and brought into law, as I said, on December 10, 1992, the Advocacy Act and the accompanying pieces of legislation.

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What those pieces of legislation meant to us was that they empowered vulnerable people with the right to make decisions that affected their lives and have the final say. Through the assistance of an advocate, they were empowered to see that their wishes were carried through. Through the implementation of the living will, all Ontarians were provided with the opportunity to determine in advance how they wish in the future, upon being required, that their health care needs and personal needs would be handled so that there would be peace of mind. Peace of mind is welcomed by all members of our society. It does not matter whether you're vulnerable or if you're disabled or a senior or frail or constricted to bed due to a long illness; everyone deserves and seeks that peace of mind. Bill 19 eliminates that peace of mind for people who are vulnerable in Ontario.

Therefore, I ask that this committee reconsider its decision to appeal the Advocacy Act. You see, under the Advocacy Act, the formation of the Advocacy Commission empowered individuals through its membership, because once and for all, vulnerable people were not being told by others what was best for them, but rather they were put in the position of power to make that determination themselves. When you lose that ability, which is taken for granted by so many, it's very difficult to regain it. The formation of the Advocacy Commission and its mandate to educate, to train and to provide the means by which the issues that have not been addressed in the past would be fairly addressed is exactly what was needed and is still needed.

As for the other components of Bill 19, we have sought legal advice on these issues and we confirm what has been presented to you by other groups over the course of these hearings—the Advocacy Resource Centre for the Handicapped from Toronto, David Baker in particular—that there are adequate liabilities and questions within the components of the amendments proposed that there could be grounds for a charter challenge. Our organization would do whatever was necessary to support any group or groups of individuals or organizations that would seek to enter into such a challenge.

As for advocacy, it is not a privilege; it is a right of vulnerable people. We are concerned about many of the provisions that are outlined in Bill 19. The withdrawal of rights advisers: we are of the opinion that rights advisers, as mandated under the Mental Health Act, should not be limited to psychiatric facilities but should be available in all institutions to avail people of their rights.

A person arrested by the Ontario Provincial Police today is advised of their rights before they are taken into custody. Why should vulnerable people receive any less? The only thing that we are guilty of is having a disability, and that, I assure you, was not by choice. If we had the opportunity to pass that challenge or that chalice on to someone else, I think many of us in our heart of hearts would, but that is not reality. The reality is that 16% to 18% of the population of Ontario has a disability. The reality is that in 19 years from now, according to the government of Canada, one in four Canadians will have a disability. The reality is that in the next 10 years the number of people over the age of 80 in Canada, and therefore in Ontario, will double. The need for advocates and rights advisers is increasing dramatically, not disappearing.

I ask that you reconsider the decision to repeal the Advocacy Act. If it's still your intention to do so, make sure you have something in its place that will meet the needs of the vulnerable persons today and in the foreseeable future, because we are talking about your brothers, your sisters, your parents and possibly your children, if not the person sitting to your left or right.

I, for example, became blind in a period of 18 months, between the ages of 37 and 39. It was not in my plans. It altered my life dramatically, and it can happen to anybody. I, like you, believed it would happen to someone else. Well, it happened to me and it can happen to you.

As for advocates, another organization I've been involved with, Citizen Advocacy, will be presenting later today and will bring forward to you stories of elderly people who have been put into hospitals and given power of attorney to children who have emptied bank accounts, sold off property, all in the "best interests" of mom or dad. There is case after case after case of this. Elder abuse takes place, therefore there is need for advocates and rights advisers. We have shelters today for battered women and their children; that takes place by partners and husbands. The person most likely to batter an elderly mother is her son—not some stranger, not some neighbour, but her son. So there is a need for advocacy and rights advisers.

I understand that you've received a procession of professional organizations coming forward and saying everything is quite all right and that they wish not to be bound by statute or regulation or guidelines, but rather, their own colleges will set up standards that will provide the protection necessary for vulnerable persons. To that I say, with all due respect, bunk.

The fact remains that these health care professionals, the ones who have vested interests, are looking for expediency and not necessarily first and foremost the individual in front of them, because of financial constraints being placed upon them.

Please remember the plight of our blood system in Canada today and that fiasco of the Krever inquiry. That was all under the auspices of these health care professionals and their colleges of standards and guidelines that led to this fiasco in Canada. Time and time again, this is repeated. We must learn from these experiences and empower individuals with disabilities, vulnerable persons, with the ability to speak for themselves. Ladies and



gentlemen, listen to those who speak from the heart and not from professional vested interests.

We thank you for your time.

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**The Chair:** Thank you, Mr La Bute. I should clarify something. This committee to date has not seen fit to restrict in any manner the method of presentation, except for time, of course. I just want to make that clear.

**Mr Tony Clement (Brampton South):** Thank you very much for your presentation, Mr La Bute. You had a lot of poignant comments to make. I would just like to agree with you when you said in your presentation that advocacy has existed for hundreds, if not thousands, of years and that advocacy was a vibrant sector in Ontario before the Advocacy Act, during the Advocacy Act and after the Advocacy Act. Perhaps you were here; we just heard from Legal Assistance of Windsor, founded in 1974, and judging by the introduction to their remarks, they seem to have done a wonderful job in the sector, representing legally and in other capacities persons who are vulnerable in our society.

Where we have a disagreement with the previous government is how best to deliver advocacy services. We don't disagree that advocacy services are necessary. We have all heard the tragic stories that have been expressed at this committee, and that's just the tip of the iceberg. No one on the government side would say that advocacy services are not necessary. It's a question of how to deliver those services to make it as effective as possible.

You talked a lot about empowerment in your remarks and how the Advocacy Commission is part of that empowerment. But is it not better to empower through individual empowerment, individual responsibility, and also, as Father O'Sullivan mentioned in his report, the moral empowerment as part of the moral duty we all have as human beings, individual responsibilities to assist those who are vulnerable?

**Mr La Bute:** Mr Clement, you've raised some excellent points, but the fact remains that volunteers and individuals, as Mr Spinoza pointed out, are limited in their individual abilities and knowledge and expertise. For example, I'm quite certain that if you wanted to purchase a diamond bracelet for your wife, you would not ask the Chairman for advice on that. You would go to a gemologist. At some point in time you require the advice of a professional to deal with a situation. I'm not excluding the role of volunteers or of individuals or family members from advocating on behalf of, with the compliance of, a vulnerable person, but the fact remains that we have accountants who assist us with accounting, we have lawyers who assist us with legal matters. No one individual can address all situations, but individuals who are trained in advocacy may assist the designated family member or the individual in having their wishes fulfilled.

**Mr Clement:** So training might be an area where—

**Mr La Bute:** Absolutely. Training and coordination, and as for having advocates throughout the province, I would suggest to you that there's no reason to reinvent the wheel. You could very easily have advocates situated working out of the district health council offices. There'd be no conflict of interest and they in turn would be in the community organizing, teaching, educating individuals

and organizations such as ours on the roles of advocacy and being an advocate and rights adviser.

**Mr Clement:** Thanks for your input.

**Mr La Bute:** You're welcome.

**Mr Duncan:** Dean, good morning. There are already examples of that: the Psychiatric Patient Advocacy Office in psychiatric institutions, which met with tremendous resistance when it was first introduced, and now, I think it's agreed, works very well.

You mentioned placing advocates in district health council offices and spoke about an issue I wanted to raise, that is, the coordination of advocacy and volunteers, as well as our view that there would be no consistent policy. I wonder if you could expound on those views for us and on other ideas you might have in the absence of the Advocacy Act as we know it today.

**Mr La Bute:** The absence of the Advocacy Act would create a void out there. There would be no coordination of efforts to advocate on behalf of vulnerable persons. Much like any organization, there has to be coordination so that the left hand knows what the right hand's doing and so that people are given correct and proper advice in a timely fashion through a mechanism such as the Advocacy Commission or, as I understand proposed, a non-profit organization that may be set up; so long as it is there to provide that information in a timely manner to vulnerable persons.

**Mr Duncan:** So coordination and training efforts potentially could be provided there.

**Mr La Bute:** Absolutely, because that is what's necessary. A person's adult children or siblings or even adult parents have the best of intentions nine out of 10 times; there's no question about that. But they're ill equipped to deal with situations they're not familiar with. If you are an accountant, I will not ask you to remove my appendix; I would go to some medical practitioner who is skilled in that. No less should be done when it comes to advocates. People require the training, coordination and the upgrading so that the information they impart to an individual is current, relevant and to the point.

**Mr Marchese:** First of all, I want to thank you for putting us through the exercise of trying to imagine how difficult it is to be in your shoes. We often forget that, and that's part of our problem as government every now and then in not addressing the needs of those who are more vulnerable than the rest of us. That exercise I think is important.

Second, on the whole issue of the Advocacy Act, I was quite taken by your comment that December 10, 1992, was a day of reckoning as the day of giving you equal status, a day that was very important for you because you were brought in and not left out. It was very symbolic and meant a lot in terms of what the Advocacy Act and the commission could do. They've taken that away. This government is saying, "Advocacy is necessary, but the government shouldn't be doing it." Well, if the government doesn't do it, who will? If we don't empower individuals through the commission as a government-instituted setup, what power do they have? The government says, "Oh, training is what we need." How do we do that training? Who's going to do that training, and for whom and what power do these individuals have? These



are the questions that leave me a bit puzzled about what they're recommending. They recommend nothing; that's our problem. We don't know what they're going to do.

Similarly, with the Employment Equity Act they said, "We're going to have an equity plan." We don't know that plan. They've repealed the Employment Equity Act. We don't know what that equity plan is all about. So we're in the dark, like everybody else.

**Mrs Marion Boyd (London Centre):** Thank you very much for coming and for sharing with us as you did. You act as a community advocate and work very hard on behalf of people. Is it your opinion that volunteer advocates can ever have the kind of ability to stop abuse from happening when it's happening, to ensure that people's rights are respected if they have no standing, if they have no official backing and no legal existence?

**Mr La Bute:** I would use the analogy of advisory boards. It's like being invited to a steak dinner but not being able to partake. Without the authority given to advocates, with proper supervision and guidance, you are unable to intervene where necessary and take the necessary steps to protect vulnerable persons. That is what we are talking about: the ability to follow the direction given by a vulnerable person and to act on that person's behalf and have the authority in statute to carry out that mandate.

**The Chair:** Thank you, Mrs Boyd. Thank you, Mr La Bute, for your most eloquent presentation today.

**Mr La Bute:** Mr Chairman, thank you very much. I welcome this opportunity, and good day to each of you.  
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GREGORY MacKINNON  
DENISE MacKINNON

**The Chair:** The next submission before the committee is from Greg MacKinnon and Denise MacKinnon.

**Mr Gregory MacKinnon:** Thank you, Mr Chair. Our submission has specifically to deal with subsection 66(12). I'll just start.

Honourable members of the standing committee, we thank you for allowing us to address you here today. We are here as parents and we have lived in a world that, fortunately, few parents see. Our daughter, Katelyn, suffers from severe self-injurious behaviour, and we don't use the word "severe" lightly.

In late 1992, when it was clear that Katie was not responding to the usually effective methods of dealing with her SIB, we were forced to make decisions that few parents must make. We could restrain her physically for 24 hours a day, with straitjackets and tie-downs. We could chemically restrain her and risk organ damage and other side-effects that neuroleptic and anti-psychotic drugs cause. We could place her out of the home, or we could use the SIBIS, the self-injurious behaviour inhibiting system.

We decided to use the SIBIS. It was prescribed by Katie's paediatrician, a caring and knowledgeable man who treated her for all the usual childhood conditions in addition to her self-inflicted wounds. The SIBIS delivers a small shock to the fatty part of Katie's thigh when she hits or bites herself. The shock is localized to the thigh and is more startling than painful.

Had Katie been born 20 miles to the east, and subject to the provisions in Bill 108 and Bill 109, we have no doubt that today Katie would be totally incapacitated by restraints, she would be sedated into complete inactivity, institutionalized, or worse. Instead, Katie is a happy, healthy 11-year-old with severe autism.

To better understand what would lead parents to make a decision like this—to use an aversive device like the SIBIS—and to put that decision in context, you should be aware of Katie's life so far.

Katie was diagnosed with autism at about two-and-a-half years of age. We were of course devastated. But she was happy and healthy and we thought we could help her function at her best with the help of supplemental programs and supports. It was immediately clear that Katie would have many of the stereotypical behaviours like hand flapping, rocking and infrequent eye contact. We learned to accept those behaviours while trying to help her develop her potential strengths. We knew we would have to be resourceful in recruiting professionals to help Katie, in the fields of mental health, education, medicine, physical therapy and speech and language.

We would like to relate some of the therapies we've tried and the interventions to help Katie navigate better in this world. Some of them did help her to a minor degree, some of them did not. None of them hurt her directly. Some were before the onset of her SIB and some after.

We took Katie to holding therapy twice a week for about two years. Holding therapy is based on the theory that the mother-child bond was somehow broken and that forced holding would help repair that bond. Holding therapy has since faded as the demand for efficacy data has increased. At about the same time, we heard about sensory integration. It seemed to us that this could be a real help to Katie. If in fact she was being bombarded with sensory input, SI could help desensitize her, thereby allowing her to make better sense of the world. We took her to a registered occupational therapist trained in sensory integration for over a year. Neither of these therapies benefited Katie very much, if at all.

We hired a private gymnastic coach, who worked with Katie at least two times a week for three years. This did help Katie develop gross motor skills, coordination and strength.

Between the ages of three and seven, Katie had three speech and language pathologists who worked with her on various types of communication, including sign language, facilitated communication, pointing and gesturing, picture identification and portable computers with voice synthesizers. Katie always had the ability to pull us by the arm and point to what she wanted, but we wanted to expand this ability so that other people would understand what she wanted.

We had Katie in play therapy and music therapy, with so-called normal peers.

We tried Katie on Ritalin, on the advice of a neuropsychologist who herself was a high-functioning autistic. That trial kept Katie awake and agitated for 24 hours.

Katie was enrolled in a cross-categorical classroom with higher-functioning kids so she'd have good role models. It was in this classroom that Katie began having aggressive episodes, and as the school year went on, the



episodes got more intense and more frequent. We took Katie to the University of Michigan child psychiatric clinic for about a year, hoping that Dr Luke Tsai's staff could help us find a reason for the aggressions and a way to help Katie control them. The treatment there consisted mostly of facilitated communication and a regimen of Anafranil. The facilitated communication was fruitless, as Katie would never use it at home, and the Anafranil made Katie more agitated.

We looked into allergies as a possibility for Katie's worsening behaviours, possibly an environmental allergy or food allergy. The environmental allergist told us we were in the wrong pew if we thought Katie's aggression and self-injury were a result of something in her environment. We decided to try a yeast-free diet, thinking that it couldn't hurt and maybe it could help. We were wrong. That diet led to an eating disorder that still rears its head from time to time.

We found that Dr Bernard Rimland was recommending megadoses of vitamin B-6, with magnesium and a natural substance called DMG, as a possible remedy for self-injurious behaviour. Not so with Katie. Dr Rimland later told us that behaviour worsens only in about 3% of the children. Katie was unfortunate enough to be in that 3%.

Just before Katie's seventh birthday, her self-pinching and wrist-biting accelerated dramatically. She also started slapping herself in the head more and more often. At first, we were advised to ignore these behaviours, as paying attention to them might reinforce them. That made sense to us. The problem was, it didn't work. Katie would pinch, bite and hit herself even when alone, so attention-getting didn't seem to be the motivation for these increasingly dangerous behaviours. While we were trying to find a reason for Katie's self-destructive behaviours, they were becoming more and more ingrained and we were losing our little girl.

By sheer accident, we found that Katie would hit less, albeit not much less, if she wore a hat. She started wearing a hat constantly and would not go without it even in the summertime. Shortly after she started wearing the hat, she started hitting harder and faster, as if to defeat whatever protection the hat was providing. She then grabbed a hood that was unzipped from the jacket and wanted to wear that over the hat. Then we saw the same process of the hitting becoming harder and harder. When the hat and the hood together were no longer protecting Katie, we reluctantly bought her her first helmet. Shortly thereafter, she would hit the helmet with all her force. Our hearts broke to see Katie bashing the helmet that she depended upon so much. She couldn't live without the helmet, but she wasn't living with it either.

We were learning what is meant by restraint dependence. Katie's SIB was worsening, even as we added more restraints. She was now wearing stiff arm restraints that didn't allow her to bend her elbows so that it would be harder for her to hit herself, but they also denied her the ability to feed and toilet herself.

We were still looking into physical reasons for Katie's SIB, putting her through CAT scans, MRIs, X-rays and blood tests. All of these tests showed that Katie's only physical problems were self-inflicted.

In addition to looking into possible physical reasons, we took Katie to Western Michigan University psychology clinic, where Dr Patricia Meinhold, a clinical behavioural psychologist, evaluated her and began working with us on behavioural approaches to Katie's SIB. That relationship continues to date, and Dr Meinhold is now a paid consultant for the school district as well.

Wanting to know more about current medications used to combat SIB, we made an appointment with Dr Leonard Piggott, a well-known psychiatrist who worked in the field of autism for 30 years. Dr Piggott reluctantly informed us that there was no effective drug for the behaviours. He could only offer anti-psychotics and sedatives. We later tried Benadryl and Catapres at Dr Piggott's suggestion. It turned out that Katie's reaction to almost every drug is the opposite of the desired effect.

#### 1040

By late 1991, Katie's helmet wasn't serving its purpose any more. She was hitting it hard enough to break off most of her hair, resulting in large bald spots and abrasions at the back and sides of her head. Katie even smashed the shell on one helmet with the force and intensity of her blows. Her eyes were constantly blackened and swollen and she had bloody, open sores on both of her cheekbones. Her wrists were bitten down to the bone and her upper arms had divots from where she chewed the skin.

The bandages we applied to her arms just became more targets for Katie, as she chewed through them. The arm restraints also lost their usefulness, as Katie could bite into her upper arms, and banging her head on walls, door jams and tile floors would take the place of her own hits. When both arm restraints and helmet were in place, Katie started biting her knees and ankles. There just wasn't any way to protect every inch of Katie from herself.

In February 1992, we were at our wits' end. Katie was alternating between living on a two-inch-thick gym mat in our living room and a padded, sectioned-off section of her classroom, being carried to and from the bus kicking, hitting, screaming and biting by as many as four people. The school had used gentle teaching and worked from books like *Progress Without Punishment* for well over a year, and now it seemed all we had accomplished was delaying the inevitable.

One day, the school called to say Katie was out of control again and they were afraid she might do permanent damage to herself. We knew this was serious, because Katie's school would never admit they couldn't control her. We picked her up from school wrapped in a blanket and drove directly to Ann Arbor and admitted her to the child psychiatric ward of U of M Hospital. That was the first night Katie ever spent away from home, and it tore us apart.

At about 9 o'clock that evening we called to see how Katie was doing and were informed by the nurse that they had given her 25 milligrams of thorazine and she was sleeping. Apparently, there was fine print in the admissions form that allowed them to use their discretion on medication without consulting us.

Katie was still groggy from the effects of the thorazine at 2 o'clock the next afternoon. When we asked what the



plan would be for finding the root of Katie's SIB, we were told only that, "Here at U of M we medicate, and we medicate aggressively." There would be no behavioural plan, no plan to enhance communication, only medication. We didn't want Katie sedated into submission, so we had her released.

For two years, we had tried the proven methods of extinguishing Katie's SIB. We tried positive reinforcements, we blocked hits, we redirected Katie's attention from the self-abuse. Katie was always overly praised when she wasn't self-injuring. The problem was that those times were becoming fewer and of shorter duration. Katie would hit and bite herself for six hours at a time, stopping only when her strength was completely depleted, but the slightest noise or movement, even the dog walking by, would start the cycle all over again, day after day after day.

In the summer of 1992, we hired tutors to work with Katie on a daily basis, hoping that the consistency might help her get herself together before the school year started. But Katie's self-injury now had a life of its own, and it was taking over hers. She could no longer bring herself to go outside and play on her swings and trampoline that she once cherished. She could make it only as far as the patio, where the urge to bash her head into the brick wall of the house overcame her. Sadly, we sent Katie back to school that September in much the same condition that she left there the previous June.

By October 1992, Katie was hitting her head and face at a rate of 5,500 times per hour. Her wrists and upper arms were festering sores. Katie was refusing to walk at all, having to be carried wherever she went. She was back in diapers, undoing two years of toilet training. Katie was eating about every third day, refusing even treats in between. She had lost six of her 54 pounds and her ribs showed through her skin. Sleep only came to Katie when she was completely exhausted and then only two or three hours a night. A daily chore at our house was to soak Katie's blood-drenched nightgown in bleach.

When giving Katie a shower in the evening, my wife would roll up her pantlegs and stand in the shower with her to prevent her from slamming her head into the tile while I tried to wash her and clean her wounds.

My wife and I watched helplessly as Katie's physical and mental health deteriorated to the point that it endangered her eyesight and even her life. It was like watching our sweet daughter get into a terrible car accident every day.

At the end of October we decided to try the SIBIS. We knew of the SIBIS for about a year, but always thought we would find some less extreme way of dealing with Katie's self-injury. When we made this decision, we were well aware of the ramifications. We knew that reasonable people would disagree with us. We were sure the anti-aversive faction would come out of the woodwork to condemn us.

Katie would get no services from the state of Michigan, as there is a directive prohibiting aid to families who use the SIBIS. Of course, we knew that the school district would not allow it in the classroom, even though their own consultant, Dr Peter Holmes from Eastern

Michigan University, later told them that it was the most humane thing they could do. But we had to help Katie, because she had lost the ability to help herself. Her SIB was consuming every waking hour.

The SIBIS trial took place on the last weekend in October 1992 at Western Michigan University psychology department. Dr Patricia Meinhold and some of her graduate students volunteered to conduct this trial.

That three-day weekend changed Katie's life, and ours. Katie immediately responded to the SIBIS. The two-hour drive home from Kalamazoo at the end of the weekend was amazing. Katie smiled, looked around and ate snacks the entire way. We hadn't seen her smile in what seemed like a year. Katie seemed as if a tremendous weight had been lifted from her.

In the next few days, about 99% of the hitting stopped. We later started using the SIBIS for the arm and wrist biting, and that too stopped almost immediately. Katie's face, wrists and arms were healing and she was eating and regaining her lost weight and she was sleeping through the night. My wife and I were overwhelmed. It was so wonderful to have our Katie back. We thought she was gone forever. We can now sleep through the night without hearing the sickening moan Katie used to make as she bit her wrists and arms through the night and the terrible slap, slap, slap that would inevitably follow.

It has now been more than three years since we started using the SIBIS and Katie is injury-free, her hair has grown back and she is healthy and happy, as you can see from the front of this. Katie no longer wears arm restraints, bandages or helmets, and she only wears hats or hoods when the weather demands it, just like the rest of us. But the scars Katie carries from those days are a constant reminder of how horrible and cruel life can be to a little girl.

We aren't here to say Katie's life is perfect now. She still has many serious deficits, both social and cognitive, and the tendencies towards SIB still appear from time to time. Katie has many obstacles ahead of her, but with the freedom from the SIB that the SIBIS provides, she can concentrate on overcoming them, instead of the obstacles overcoming her.

Finally, it's obvious that Bill 19 won't affect Katie or our family. We are here now because there is now, or will be, a Katie in Ontario, and she'll deserve the best quality of life her parents can give her. There is, or will be, Canadian parents who will have to face the decisions we faced. There won't be many. Our family is the only one we know of in Michigan, but there will be one or two, and it would be a shame if that Katie was denied effective treatment by a well-meaning government trying to protect her.

If in the course of these readings you come upon people who refer to themselves as advocates for children or advocates for the disabled who oppose the decisions we've made for our daughter, please ask them if all the so-called non-aversive treatments combined have a success rate of 100% in stopping self-injurious behaviour. When they answer no, please remember Katie's story and think of the beautiful face on the front of this submission.

My wife and I again thank you for allowing us to address you here today.



**The Chair:** Thank you, Mr MacKinnon. We have three minutes each caucus.

**Mr Duncan:** Thank you for your presentation. I don't have any questions.

**Mrs Boyd:** Thank you very much for coming and for sharing that with us. It takes a lot of energy to do that. I'm curious about the prohibitions within the state of Michigan and in your school district. Do they still pertain? You are still having to use this on a private basis?

**Mr MacKinnon:** The SIBIS is with Katie in school now, after negotiations, and the state still has a directive prohibiting aid to families who use the SIBIS.

1050

**Mrs Boyd:** Can you tell me on what basis they put that directive in place?

**Mr MacKinnon:** I don't remember the wording they used, but it's an aversive treatment.

**Mrs Boyd:** They prohibit aversive treatment.

**Mr MacKinnon:** Yes, they prohibit it.

**Mrs Boyd:** One of the suggestions that has been brought to us in the past is that perhaps, given that there are very few people who are shown to be helped by this kind of treatment, the option might be to have a process whereby the kinds of other treatments have all been tried and can be shown, to a court or to a capacity and capacity board, that they have not worked and that then there is that check and balance. Do you think that's a reasonable position for a government to take?

**Mrs Denise MacKinnon:** Within a time frame.

**Mr MacKinnon:** Yes, it depends on the time frame. Katie didn't have that long. Had the process been, say, a three-year process, plus appeals that the state would do or whatever, Katie didn't have that long.

**Mrs Boyd:** No, it would have to be a shorter process, but you did now about it for about a year before you tried it, so there would have been a period of time in there for you to look at that as a possibility.

**Mrs MacKinnon:** Which we did.

**Mr MacKinnon:** Right. We knew about the SIBIS for a year, but Katie's self-injury had been going on for two years, so we had ruled out—

**Mrs Boyd:** Tried everything.

**Mr MacKinnon:** —a lot of the methods earlier because they were just standard methods that worked for most kids.

**Mrs Boyd:** The problem for us is that we have had psychologists appearing in front of us who seem to believe this should be generally available to lots of people. We certainly had one yesterday in London who uses this in his office on a regular basis and seemed to think it was unreasonable for there to be any kind of prohibition against this. I gather you really believe that this should be available as a last resort in cases like yours, rather than generally available for behaviour control.

**Mrs MacKinnon:** Right, and with our daughter, it's a prescription from a doctor. You can't just go to Radio Shack and buy it.

**Mrs Boyd:** No, no one was ever suggesting that, including the psychologist, believe me.

**Mrs MacKinnon:** Some people don't realize that it is a prescription.

**Mr MacKinnon:** It is not a device to be used for hand-flapping or rocking back and forth.

**Mrs MacKinnon:** Life-threatening behaviours.

**Mr MacKinnon:** I don't think a parent would allow that. I give parents more credit.

**Mr Klees:** Thank you very much for your presentation. Perhaps you could, for the benefit of the committee, just give a very brief description of what this procedure does and how it works.

**Mrs MacKinnon:** If Katie should inflict, hit her head, bang her head, we have a remote and she wears a little box on her thigh. We say, "No hitting, no head-banging," and we press the buttons and she gets a half a second shock on a 9-volt battery. We don't even know why it works for her, but it stopped the cycle and she even welcomes it. She even hands me her leg set because she doesn't wear it all the time, and wants it on her leg. It prevents her from—

**Mr MacKinnon:** If she's in an agitated state, she'll pick it up off the desk and hand it to us.

**Mr Klees:** And have you felt this shock yourselves?

**Mrs MacKinnon:** Yes.

**Mr MacKinnon:** Oh, certainly, more than she has.

**Mr Klees:** Could you compare it for us? What would it feel like?

**Mrs MacKinnon:** Like a light socket.

**Mr MacKinnon:** It's less than—you know, when every kid puts their finger in a light socket, it's less than that.

**Mr Klees:** Okay, we've had presentations from a family whose son benefits from faradaic stimulation. The story is very similar to yours. As you know, the previous law in this province restricted that use and this bill allows that to be used. I'd like to get your thoughts as well, because we have had presentations before this committee from advocates who oppose this and would like the previous law to stay in place and in fact, in their presentations, refer to this as cattle prods. I take personal offence at that terminology. I'd like to get your reaction to those who call themselves advocates for vulnerable people, but choose to use that terminology in this context.

**Mr MacKinnon:** I think it's very divisive, especially in light of the fact that we have more in common with those people than we have differences with them. We have this one difference with them and Katie is the beneficiary of this one difference and we get called names. We've been called worse than just using a cattle prod. It's a shame it has to come down to that. Of course, we take offence at it, but we've learned to live with it and we probably will have to live with it for a while.

**Mrs MacKinnon:** It's so rare that a child would develop this extreme behaviour. A lot of these people are passing judgement and they don't know us, they don't know Katie, they don't know what treatments we use, they don't know what doctors we've gone to. How our child suffered. We agonized over this decision, because we knew the ramifications, we knew these people would come after us, but we had to save our daughter's life.

**Mr MacKinnon:** And we knew that what I think is called ARCH here—no services from them, we knew that. We knew all of the ramifications. We knew that Katie would not get services, that we wouldn't get respite, that there would be no help from any government agency over there.



**Mr Klees:** So the prohibiting legislation in Michigan certainly caused your daughter a great deal of pain and agony over a number of years.

**Mr MacKinnon:** It did and it cost her in time, pain, and it's still costing her in services that she should be eligible for.

**Mr Klees:** We commend you for your courage.

**The Chair:** Thank you, Mr and Mrs MacKinnon. Not only is your love for your daughter, Katie, evident, but for the unknown children and parents who are agonizing at this moment of the same ailment.

#### CITIZEN ADVOCACY WINDSOR-ESSEX

**The Chair:** The next submission is the Citizen Advocacy Windsor-Essex, Joyce Zuk, executive director. Good morning and welcome. Ms Zuk, I understand you have with you a Stuart Tait and a Dan Frimer.

**Ms Joyce Zuk:** Yes, we do this morning, and they'll be copresenting with me. We'll let Stuart Tait do the opening remarks and introduction.

**Mr Stuart Tait:** First of all, thank you for the opportunity to be here. I am the vice-president of Citizen Advocacy, Stuart Tait. Our executive director is Joyce Zuk, and Dan Frimer is one of our people on our board of directors.

I know you're looking at several issues here and let me say that we do not intend to address the Substitute Decisions Act or the Health Care Consent Act. We can answer some questions, particularly Joyce, on her exposure to those with the clients we serve. However, we view ourselves as advocacy experts, so that's what we're going to talk about.

Just a little background: We serve Windsor and Essex county, so this is a citizen advocacy group of Windsor-Essex. As to who we are and what we do, I might vary a little bit from the preprinted text. We are a non-profit, and I might say very non-profit, charitable organization and we provide non-legal advocacy to the frail, elderly and disabled.

We are a small organization—four full-time employees and the rest of the staff are volunteers, including the board of directors. The board of directors represents several different groups. Several, like Dan Frimer, have actually come through our program and they keep us honest in what we do. Several are like myself, retired senior citizens, but close enough to the frail and disabled senior people that we can understand where they are and where we're going. We have a lawyer on the board, but in spite of that, we manage to be productive.

I'd like to share with you what we term as long-term advocacy versus short-term advocacy. Let me say, we are funded by three primary groups. About one third of our money comes from a government grant, about one third from United Way and about one third we scramble any way we can by running bingos, golf tournaments, fun runs, anything else we can to make a dollar.

1100

Our money that comes from outside specifies that we are a long-term advocacy group, and our long-term advocacy program will go something like this: Our permanent staff in the office will go out and recruit volunteers. They will then train them in the advocacy skills they need. In

the meantime, we have a waiting list of candidates for our service. The coordinators in the office will match the volunteer with the person requiring our service, and this is a long-term commitment. We like to think of it almost as lifetime, because in many cases it has been. We're establishing a relationship in partnership here that will continue and many times blossoms into a very firm friendship between a volunteer and a disabled person.

In performing this role of long-term advocate provider, we do run into requests coming to our office that don't really classify as long term. They're short term. It's some temporary condition of somebody where they can't provide for themselves, but with, I could say, a quick fix-it, we can take care of it. Although we're not primarily in that business, we can't say, "No, we won't do it." But it does take the valuable time of our permanent staff to provide this short-term service. What we find is that our long-term program suffers a little bit because of that.

Let me go back to our text a little bit here. This morning we'd like to talk about who can provide advocacy when we repeal the Advocacy Act. The statement we've all heard is, "It's family, friends and local charity organizations." This is fine, and certainly in a lot of cases family and friends do provide this support. However, you should be aware that our contacts in the office frequently prove just the opposite: that family and friends sometimes create the need for the support.

There's the elderly mother who's being abused by her son, the friends who are taking advantage of the money situation of a senior citizen. There are several instances that have come to our attention where family and friends are the cause of the problem, not helping to get rid of it.

The other thing we know is that family nowadays gets scattered all over the country and frequently are not in a position to help.

So while not saying that family and friends can't help, we say that many times they're either not in a position to help or sometimes create the problem itself.

Let me jump in the text from item 3 to item 4, because if we say family and friends cannot provide this service, this missing void in the Advocacy Act, then our third alternative is our community organizations. So what can we do and, as Citizen Advocacy Windsor-Essex, what do we feel we can do to provide service in this situation?

One of the big problems is we're not really empowered properly to provide the service we sometimes have to do. We go to a hospital for information and they're not willing to give it to us because we're not family. So one thing we think we need to better provide the service is better empowerment to do the job.

I don't know if any of you read the horoscopes in the newspaper. I never read that trash, but mine last night said this: "Redouble your efforts to create a secure and loving environment for someone who is vulnerable." I thought: "Gee, is that appropriate. I will vary from this text a little bit to try and do that."

When we say, what can we do as an organization, I'll share with you something we have been thinking about for some time, and that is, if we had some additional money—and I'm not talking anything like the \$18 million you're tossing out with the Advocacy Act. We are a very tight-fisted organization and can perform miracles with a



few dollars. But if we had some additional money to hire coordinators who could devote their entire time to short-term advocacy and develop a program for short-term advocacy similar to the one we have for long-term advocacy—it's a different type of volunteer entirely.

From a volunteer who builds a lifetime relationship with long-term advocacy, a short-term volunteer would have to have a different time commitment, to jump in quickly, maybe for several days, and then be involved for maybe one day the following week and one day maybe two weeks later—case closed. Then they go on to another situation. They need a lot more training in the agencies that are available to provide service. They need a lot different schedule of availability of their time to volunteer for this kind of thing.

But we think it's possible. We've talked about trying a program like this, if we ever got in a position, which we never have, of having surplus funds from our fundraising events. We would like to try this, because it frees up our existing coordinators to devote more effort to our waiting list of people requiring long-term advocacy.

So basically, overlooking all the nuts and bolts and fancy words, we're saying we'd like a chance to pilot test a program for short-term advocacy similar to the one we run for long-term advocacy. We don't know all the problems we'd get into using volunteers in this kind of position, but we're willing to give it a try and we're willing to be the pilot area in the province for that.

I'm going to jump back to the text now and jump it over to Joyce, and she'll probably want to go back to item 3.

**Ms Zuk:** Yes. Thank you very much, Stuart. While we're stating that volunteer advocates can be very useful in the facilitation of advocacy and that we are interested in developing a pilot project where we could offer short-term advocacy, that's not the end of it.

Stuart has already highlighted that volunteer advocates and even our paid staff do have difficulty when they try to advocate in our community. We are pointing out that without legal or legislated power to advocate on someone's behalf, advocates are often unable to resolve problems, obtain information or articulate issues to appropriate individuals in positions of authority. It is for this reason that we as an organization supported the Advocacy Act and now mourn its demise.

The act provided for the creation of paid advocates who were empowered through the legislation to actively support vulnerable people. The legislation provided for advocates who were able to enter institutions and care facilities and gain access to records. And The Advocacy Act legitimized advocates acting under the Ontario Advocacy Commission who were acting on behalf of vulnerable individuals.

As an agency that provides advocacy to vulnerable individuals, we've already mentioned that we're limited in the number of ways that we can accomplish this. Let me point out a few examples that we've cited in our text.

Administrators of care facilities are not obligated to meet with us when we request a meeting to articulate a resident's concerns. I can tell you, this incident has happened time and time again in our community. They often will meet with us, but they do not have to. It's a

real problem. It's a problem for our volunteers when they're going in, and it's a problem for our paid staff.

**1110**

Signed authorization documents for release of information, when we supply them to care facilities or to government offices, aren't always accepted, and the common response that we get is, "Have a lawyer draft one up." Well, the reason why people are calling us is they can't afford a lawyer, and the legal clinics, as I'm sure you're all aware, are limited in the amount of work that they are able to perform.

If we are called to go to the hospital to visit someone, more often than not we are not admitted or given access to that individual because we're not a member of the immediate family.

What happens is that our efforts become a hit-or-miss type of thing, and that's no way to offer advocacy in our community.

The second point we want to address is the government's contention that agencies and organizations are equipped to provide advocacy to the vulnerable. As we've already mentioned, we do applaud the government for recognizing the work that we do in the community, but as we've stated, with the repeal of the act, we're limited as to the legitimization that advocates have.

Also, in this time of fiscal restraint, many of those agencies and organizations that provide advocacy are having their funding cut or reduced. The Ontario Advocacy Commission stated that the government could not have picked a worse time to remove itself from the business of advocacy in light of the cuts those agencies already providing advocacy are facing, and we ourselves have received cuts from one of our government funders. We recognize what the reality is, but it also impedes our ability to offer advocacy.

The rest of the presentation that I will be reading is on behalf of Dan Frimer, and he has asked me to read on his behalf.

The role of volunteers in advocacy has received a great deal of recognition as of late, and as I've already mentioned, we're pleased that the government recognizes the work that volunteers and volunteer-based organizations are providing across the province.

Volunteers can perform advocacy, and I can assure you that they do so effectively. However, volunteers require initial and ongoing training as well as support. Recruitment of volunteers to advocacy programs is also required on an ongoing basis. We've got to get the message out there. And as Stuart has already highlighted, for this reason we would condone a pilot project to give us a chance to see if we could do this.

There is a need for a consumer-driven approach to advocacy. The process leading to the creation of the Advocacy Act was a consumer-driven one. Individuals representing the disability community and seniors were empowered to take an active role in establishing the legislation that would protect their rights. The right of disabled people and seniors to articulate their concerns is critical to the legitimizing of any process which will create new legislation. The right of disabled individuals and seniors to make their own choices is paramount.



The need for systemic advocacy is also ever present in Ontario. Ontarians with disabilities are very aware that their rights are in jeopardy if not safeguarded. Issues such as income maintenance, transportation, employment and accessible housing still require a great deal of work. It required a great deal of work to get Dan to attend these hearings this morning, because there are only two forms of accessible transportation in this community and one was not accessible today.

The Advocacy Act empowered the Advocacy Commission to work towards effecting positive change on systemic issues on a province-wide basis. The government has acknowledged the importance of communities in addressing the needs of vulnerable people, but unless a province-wide mechanism is in place to examine broader issues, there will be little chance to effect overall change.

Finally, in our submission this morning, we do have some recommendations. We feel if we're going to be part of the solution, we have an obligation to look to the future. We have six recommendations, and they are as follows:

(1) The government must take an active role to ensure that advocacy is available to vulnerable individuals. I know that it's already been stated this morning that the government is not withdrawing itself from advocacy, but I'll assure the committee that the disability and the seniors' community feel that this is exactly what the government is doing. To repeal the act without suggesting replacement legislation is problematic and has left that impression.

(2) The government must ensure that any body, structure or system created to provide advocacy is one which is conflict-free. We've already discussed the issue of family and friends providing advocacy. It's very difficult, often, for families to remain free of conflict, especially when making decisions regarding treatment and care of the ones that they love.

(3) The government must move to develop legislation to protect the rights of vulnerable persons if indeed the act is going to be repealed.

(4) The government must ensure that any process which may result from these hearings is one which is driven by members from disability communities and seniors.

(5) The government must address systemic advocacy issues in order that changes to the present system of service delivery are realized.

(6) If the government does not intend to develop a central structure to deliver advocacy province-wide, they should look at providing additional funding to community organizations to train advocates and implement local advocacy programs. Even so, with that, they're going to have to come up with solutions for those communities in this province that presently don't have any volunteer advocacy structures in place.

**The Vice-Chair (Mr Ron Johnson):** We're going to move to questions. Each caucus has four minutes.

**Mr Marchese:** Thank you for your presentation. I found it very useful because you raised concerns that are important for us to address. First of all I'm sad to say that the government, by repealing this section, has effectively withdrawn itself from advocacy. It's done so

by repealing it, so it contradicts all of your recommendations, in a way, which I'm not sure how we'll recover, from the suggestions you make, based on the repeal of this Advocacy Act.

This government is saying, "We don't need institutionalized advocacy," meaning the government should not be in the business of providing advocacy. That's what they say. Then they say: "We should provide training. Do you agree with training?" So you end up saying, "Yes, we do."

**Ms Zuk:** Yes.

**Mr Marchese:** "What about volunteers? Should we train them?" You'd end up saying, "Yes, we need training for volunteers." Then what do we hear from the government? Nothing. That's the problem. We've got a problem. The problem you speak to is that individuals are advocating out there and organizations are advocating out there and so are some family members advocating out there.

Stuart mentions that friends and family sometimes create the need for your support, and you recognize that because you're in the business of providing advocacy. You talk about the limitations of organizations—not having the authority to intervene—so it's hit and miss, as you said. That's the problem we've got. Any volunteer thing this government recommends is purely voluntary.

We train people in organizations, let's say, even if they put in some dollars I'm not sure, but then we have the problem that you talk about: How do we get the authority to intervene? We've got a problem.

I think this government has an obligation to tell you and to tell us what they're going to do—not later, once they've repealed it, where we won't know or have a sense of what they will propose, but now, so that we can say we agree or disagree or organizations like yourselves can say you agree or disagree. You propose a pilot project; it's very nice as a short-term measure of advocacy, but that's only a pilot project. Even if they were to agree to that, we've got a problem because it's not systemic, which was the intent of the Advocacy Act and the commission. Do you have any response to that?

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**Ms Zuk:** Perhaps I'll respond first. Of course, everything you've just stated we agree with 100%, but we're trying to exist in the real world too. We're having hearings here. It's been proposed that the act is going to be repealed. It's had its first reading in the House. I don't know what's going to happen out of these committee hearings. I heard, I've been told, I've read that the government wants to get out of the business of advocacy, but I also heard just this morning that the government doesn't want to get out of the business of advocacy.

We would like some clear direction from the government. That's why we said that to repeal the act and not suggest any replacement legislation or what they're going to do next creates problems for us. So we're trying to work within the fiscal reality that there's not money out there, but the bottom line is that advocacy is a right. I'm sure that you've heard this across the province.

The government has an obligation to assist vulnerable people and to fund a body, create a mechanism, something to support these people. Hey, we'll do it, we'll con-



tinue to try to do it on a volunteer basis, but if anyone in this province thinks that we're going to do it effectively and systematically and province-wide, they're dreaming; we can't do it. But we're going to try because we care.

**Mr Clement:** Thank you very much for your presentation. Stuart, I just want to say that you presented, on behalf of your organization, an excellent model of how things should be done in the community, how to empower people in the community, and you made a lot of practical recommendations on how to create a system out of that that's better. Relatively speaking, these organized efforts are relatively new, if you look at the whole history of Ontario, but it's been growing very rapidly to meet, obviously, a rapid demand. But you've been doing an excellent job out there, and I wanted to praise you for that.

People told us that the way to deliver these advocacy services was not to create another institution.

**Mr Marchese:** Who told us that?

**Mr Clement:** I knocked on 20,000 doors in my riding, Mr Marchese. I just want to say to the members opposite that if they think that creating another governmental body is going to solve all of the problems we have heard over the last two weeks, they're chasing a mirage. In fact, they are purveying a mirage. We believe in empowering individuals, individual responsibility and duty but also individual empowerment.

**Mr Marchese:** How do you do that?

**Mr Clement:** That's what we're here to find out, Mr Marchese. We're here to take input. You condemn us when you say that we aren't listening to people and then when we want to listen to people you condemn us again. Maybe that's the role of the opposition, but I'm finding it a bit tiresome myself.

I just wanted to put that point on the table, that institutions can cause problems as well as family members. We're not saying that family members are 100% perfect along the way but I guess our inclination, by and large, is that family members love the vulnerable person in their life and want to do the best for them.

In the exceptions, that's why we have laws and public guardians and trustees and substitute decision-makers, health practitioners, whatever, that can move in to protect the rights of the vulnerable individual. I'm just curious why you, being a member of a very successful organization, think more government institutions are not a mirage?

**Ms Zuk:** If I could respond to that one, I appreciate what you're saying, that you believe that family and individual empowerment and everything else is the direction to head in. But I'm telling you, Mr Clement, the very reason we exist is because family members don't take care of their own. This is the reality.

We feel that 389 facilitations of service last year from individuals who called us and did not call their family and did not call their friends—you have to be aware, and we don't want to admit, that it's family members and friends who often commit abuse in these circumstances.

I don't know what the answer is, but we're suggesting that the government has to take a lead here. I know that you've just stated that the office of the public guardian and trustee is there, that it's set up to intervene. They cannot possibly get out there and investigate all the issues of abuse.

When you have to prioritize, someone who's being abused in a care facility is a higher priority than someone who maybe gets his vets' pension cheque taken by his daughter every month to go and buy alcohol.

**Mr Clement:** I'm not denying abuse occurs, Joyce.

**Ms Zuk:** But I think it's more rampant than what the government knows.

**Mr Clement:** You seem to paint a picture that all family members in our society are out to damage.

**Mr Dan Frimer:** No. No.

*Interjections.*

**Mr Clement:** That's what I'm hearing. So please correct the record.

**Ms Zuk:** We do work with many families that wish to assist their vulnerable individual, but I'm telling you we also work with a lot of people who are being abused by their family, or even more prevalent, with people who don't have family or friends or a societal contact and who are isolated. We have a number of files right now from individuals in Essex county, outside of the urban centre, who are isolated because of their disability or their age, particularly women who are seniors. Their children have moved away, their husbands are deceased and they are alone. What are we going to do about those people? This legislation doesn't take them into account.

**Mr Clement:** We're not the solution you're seeking.

**Mr Duncan:** I knocked on 32,000 doors and this issue didn't come up once. In fact, there wasn't one of your people elected for 50 miles.

Let's talk some more about the substance of the issue, Ms Zuk. I'd like to review with you for a couple of moments, given that they are going to get rid of advocacy—they've said that. The bill is forward. You've presented six recommendations. I'd like some comments from you around the replacement for advocacy. We're looking at things; for instance, we've talked about the PPAO expanding its mandate and providing enhanced training and those kinds of initiatives for organizations like yours. Can you expand on that a little bit and share with us some of your views? Given the fact that they acknowledge they don't want to proceed with any kind of advocacy, can you share with us some of your views on what perhaps—

**Ms Zuk:** If the government does not want to create a bureaucratic structure to deliver advocacy, there is still a possibility that legislation can be put into place to address some of the issues that we're dealing with on a regular basis. Let me give you some examples. We, as a non-profit, volunteer-based group, solely deal in the business of instructed advocacy. So when we advocate on a vulnerable person's behalf, they must provide us with instruction. That's the way it works. There are legal implications if we act for somebody without getting their consent, and that's not what we're in the business of doing. The office of the public guardian and trustee has the authority to take action in situations without getting consent, obviously.

Two problems that are coming up quite often are with elder abuse and with developmentally disabled adults. No one who's in the business of service provision is obligated to report incidents of elder abuse that they come across unless they view these incidents in nursing homes

and those types of facilities. What happens is that our office will get a call from the homemaker who's been cleaning the home of an elderly woman whose son or daughter, whatever, is abusing her. We go out, work with this woman to empower her and encourage her to the point of bringing her concerns forward to the proper authorities. For a number of reasons she doesn't want to go any further.

We were called out on a case about six months ago where a woman who was developmentally disabled was being sexually abused by someone who was making deliveries to her home. We're working with her, trying to encourage her to move on to the appropriate authorities to make her concerns known, trying to work with her to show her that this is a problem, and we can't. There's no legislation that obligates us to do something about it.

Help us out. We want to be obligated to do something about it. We want to be able to call a paid advocate to come and do something about it. That's something the government could do to help us out. It tears us apart when we hear about these cases because, as a community organization, volunteer-based, we have no authority to act. We're looking now at developing a moral code, something to guide us and instruct us further internally, but some provincial directive would really assist us.

**The Vice-Chair:** I'm sorry, the time has expired. I want to thank all of you for your presentation to the committee.

**Mr Tait:** We thank you for this opportunity.  
1130

#### TERRI GRANT-GALLI

**The Vice-Chair:** We're going to proceed with Terri Grant-Galli, who was scheduled at 2 o'clock. She'll fill the slot at this time until lunch. Ms Grant-Galli, you'll have 30 minutes for your presentation. You may want to allot some time for questions.

**Ms Terri Grant-Galli:** Good morning, everyone. I'm not as relaxed and calm as I was hoping I would be when I did this presentation. I was expecting a couple of hours of being able to observe other people's. What I'm going to do, if it's not too offensive because of my state of nervousness, is basically read the report that I've given you and hopefully be able to add some other insights.

I'm currently employed as a rights adviser with the Advocacy Commission and provide services to all facilities, hospitals, nursing homes, long-term-care facilities and private residences between Windsor, Chatham, Leamington and Sarnia, and on occasion London. Although I'm part of a team, I am the only advocacy employee in this region. I've worked extensively in the past with community-based organizations that have advocacy as a cornerstone of their purpose. This includes the Multiple Sclerosis Society, the AIDS Committee of Windsor, the Consumer Survivor Alliance of Windsor and Essex County and the Ontario AIDS Network. My combined work with these groups probably totals about 20 years.

The population I serve as a rights adviser in the tri-county area is approximately 600,000 individuals. Of this number, it has been estimated by the district health councils in the psychiatric hospital restructuring consulta-

tion and discussion paper of last year that approximately 35,000 persons are currently suffering from serious mental illnesses such as schizophrenia, mood disorders, organic brain syndrome, paranoia and other psychoses, severe personality disorders, and dual diagnosis disorders.

This number is substantiated by the Ontario Mental Health Supplement which indicated that 2% of the general population is so affected. This number does not necessarily include child or adolescent patients, the psychogeriatric population, people suffering from addictions or individuals who are developmentally handicapped.

Since proclamation of the act on April 3, 1995, I have seen approximately 550 people in the course of my work. These individuals were people whose rights were affected either by the Mental Health Act, the Substitute Decisions Act, the Consent to Treatment Act or the Advocacy Act.

First a bit about how I do my job. I work out of my home, on my own personal computer, using encrypted access not connected to the Internet, for security reasons, with the technical assistance of a fax machine-copier, a telephone and a pager supplied by the commission. I'm scheduled to work 40 hours a week and on call an average of 47.75 hours additionally. I can respond to any emergency within my region day or night for a consent to treatment issue, for example, within two hours, depending on travel time. I use my own vehicle, which I personally insure. I'm reimbursed the lowest amount per kilometre allowed by the province. There is no regional office, thus there's no overhead. All of the intake and referral is done through a 1-800 number in Toronto.

This is a very cost-effective method of service delivery. The most important features of this system of service delivery are the consistency, the expediency and the accountability. The time lines legislated for rights advice delivery are tracked by the system, and we must call in completed visits and the results immediately. This level of accountability is crucial to ensure that the visits are completed, and if there are any additional problems or issues that need to be addressed—for example, the need for an interpreter service or any other special circumstances so these issues can be dealt with quickly and thoroughly.

I dress semi-casually, as I'm sensitive to the fact that most of the people I see are in johnny shirts and paper slippers, sometimes in seclusion rooms with a mattress on the floor. I deliver the information the patient needs in a way they can understand it, laying out their options in a way that informs but does not influence their decision, and if a review board is requested, make the application, fill out the necessary legal disclosure forms and applications, and make the application for the hearing.

For those of you who are of the legal persuasion, you recognize legal aid applications. They're very long, tedious and difficult forms, particularly to people who are vulnerable, ill or upset. They have to have complete information on all the assets they may have ever had in the last 10 years and it's quite daunting for people who are ill.

Often this requires more than one visit due to the health of the patient. If they are very ill or unable to understand the information on my first attempt, I return



and give the information again, and will return as often as required to make sure they understand this information. I do not make decisions for the patient, but listen carefully to enable each individual to do what they feel they need to do in a way that makes them comfortable. Also, if the patient chooses not to hear the information, I leave and let them know they have the ability to call me back for consultation later.

In discussing this issue with nurses and doctors about how rights advice was handled in the past, I discovered that the service was spotty and sometimes non-existent. Duty council was often assigned to this service and the quality was variable. I've been told that certain lawyers were terrific, taking as much time as necessary to ensure the information was understood by the patient, but just as often, lawyers were pressuring patients to apply for review board hearings, promising them early release from hospital, which may not have been a realistic expectation, or not bothering to inform the patient if they were uncomfortable with the patient.

For example, if they thought the person was violent or disruptive or if they were suffering from a condition that perhaps made them erratic in their behaviour or if their physical condition was something that was unpalatable to the legal counsel, they would choose not to give the information, sometimes saying things like, "Well, maybe this person doesn't really need to know this anyway."

Many of the lawyers I've dealt with since proclamation have expressed great relief with being able to spend more time in preparation for hearings rather than filling out legal aid applications and speaking to people who did not want or need their services.

It is recognized in this community that, without a centralized system, the service cannot be monitored for efficacy and consistency, ensuring all Ontarians equal access to justice. I've never heard a complaint about the services of the intake and referral department of the commission, but rather praise about the thoroughness and the time taken to explain to staff, patients and the public the legislation and its implications, as well as referring to advocacy services available within the caller's community.

If someone were to call from the general public requesting information about what advocacy services could be accessed for perhaps a gerontology issue, they would have the complete list of what's available in the province and be able to give them concise information immediately, and if they couldn't find it immediately they'd find it and get back to the individual quickly.

Some of the misconceptions the public has about the commission and its role have been deliberately perpetrated by its detractors. An editorial that appeared in our only local paper on Monday contained numerous blatant inaccuracies and untruths from the role and actions of advocates and rights advisers to the budget of the commission to the lack of support in the community for the role of advocacy.

I know this group has heard from the nurses' association, from the College of Physicians and Surgeons, and from individual hospital representatives claiming that the existing legislation was an impediment to their work. I challenge that these assertions apply in this community.

These professional regulatory bodies were charged with the education of their counterparts with regard to the legislation and did not effectively pass along the information required to implement it. They did not do their job.

Time and time again I was asked by doctors, nurses and facility staff to explain portions of the legislation and how it applied to their work. I answered these questions and referred them to their professional associations for further information. Each facility educated its staff, with varying degrees of success and thoroughness. As recently as last week I was called in to see a patient held in seclusion at a local hospital on a form 3. I'm hoping that people understand the lingo here. Form 3 is a two-week psychiatric incarceration. The person has the ability to apply for a review board hearing but the doctor has the right to keep the person in the hospital in seclusion, and medicate and treat them for the period of two weeks.

The nurse in charge of that patient usually worked nights and we had never met. She was unaware that rights advisers were called when people were put on forms and told me directly that she felt the patient didn't deserve to have rights because he was violent and unpredictable. There is still the conception by some that rights are to be earned and not inherent or protected by the charter.

My first visit as a rights adviser after proclamation was a consent-to-treatment issue, a patient with advanced stages of anorexia. I was met by a nurse in the pastoral care centre when I arrived and was told what she wanted me to do was to inform the patient that she had no choice in her treatment options and that she had to go along with the proposed treatment, rather than the truth, which was that she could appeal the finding of incapacity.

The nurse was angered when I explained that the patient did indeed have the option to appeal and threatened to disallow my visit.

The patient did not challenge the finding. She had been so beaten by the system by that point she realized it wasn't going to be worth her while. The hospital resumed its treatment. My initial exposure to how some individuals in a position of power perceive the rights of others was not a positive one. Fortunately, some facilities have recognized that the health care professional is the patient's first advocate, and welcome the autonomy and dignity this legislation can provide for their patients.

Since then, I've had many experiences that have underscored the importance of making information available to vulnerable people and perhaps, more importantly, a mechanism that ensures that they are heard when it comes to making decisions around their care.

In June, a 68-year-old woman with a history of manic depression but otherwise excellent health was hospitalized for psychiatric treatment here in Windsor. Her condition was brought under control by medication, but while hospitalized her children decided she should be admitted to long-term care and give up her rent-controlled apartment, her friends, her pets and the comfort and familiarity of her neighbourhood; she'd been there for over 60 years.

She was made incapable of consenting to treatment, for placement, and for the administration of medication to control her manic behaviour. I was called in to give her rights advice and found that she was most distressed at



the thought of being put in a nursing home "with all those old people." She's a very vibrant woman, a lot of energy and an amazing contributor to her community.

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After lengthy discussions, she decided that she agreed that while she may be incapable of making decisions around her medication and understood that this was necessary to control the behaviours, she was truly capable of living independently otherwise. She decided to challenge the placement issue, conceding the medication issue. Visiting nurses would monitor her medication. She agreed to see her doctor regularly, and she's been living alone, successfully coping with community supports since her discharge almost eight months ago.

She's avoided living in a nursing home and the expense and stress around that by careful utilization of the resources in the community, simply by acting on her options and having someone listen to her. She and her family are very pleased with the outcome and have agreed to revisit the issue of a nursing home accommodation should it become necessary in the future.

Her fears have been allayed about subsequent long-term care, but she doesn't have to go any sooner than she wants to go. She's able to live in her apartment on Goyeau and do what she needs to do to get along in her life: go to the seniors' centre, visit with her friends, keep her cat, all the things that make her life worth living.

An elderly woman suffering from Alzheimer's was in a county nursing home for several years, abandoned by her family—their only contact with the home was a mandatory care plan meeting held annually—and they chose not to visit her during that time. At one of the meetings they insisted that a charge of \$50 monthly for her disposable diapers be eliminated from the plan so the money would accrue in her estate, and she be furnished with cloth diapers that caused her considerable discomfort and skin eruption.

The home continued to furnish her with paper diapers, drawing the money from a discretionary fund for similar circumstances. Her pension had been automatically deposited into a trust to cover her expenses at the home, but inexplicably, the cheques stopped coming for several months. Upon investigation, the manager of the home found out the children of the patient had called and written the pension administration office and, forging her name, had informed them that their mother had been discharged from the nursing home and was being cared for by them at home. This woman required 24-hour care.

The home, concerned for the financial security and the apparent abuse by the family, had an independent capacity assessment ordered and involved the public guardian and trustee, who subsequently investigated and pressed charges of fraud. Without the legislation as it stands, the home would not have been able to protect the interests of this patient.

I also have to let you know that these anecdotes I'm giving you are very emotional for me, because some of these people are so desperate. They are so alienated and so disempowered by systems and people who are there to protect them that it's shocking, and I wish I could take each of you around with me for a few days. I really think that would be the best education any of you could have.

Over the Thanksgiving weekend, I was on call in the London area. I was called to give rights advice to two patients in Victoria Hospital, both elderly people suffering from broken hips sustained in falls, scheduled to have surgery to repair the damage the next day. Both patients had psychiatric histories. One of them, a 69-year-old woman, had been a long-term patient—40 years of institutional care—at London Psychiatric Hospital with a diagnosis of schizophrenia. The other patient, a 78-year-old man, was a resident of a nursing home, with over 50 years of institutional care, and considered catatonic schizophrenic. Both patients were made incapable of consenting to treatment. The proposed treatment was to set the fractures.

When I arrived at the hospital at 8 in the evening, the charge nurses expressed surprise that I had come out on Thanksgiving and that it was even necessary to give rights advice to this type of patient at all. The staff informed me that the patients were both non-verbal, that the female patient had not eaten since her admission the morning before.

The staff had attempted to get consent from the brother of the female patient over the telephone but he'd refused, stating he didn't want to interrupt his dinner plans and he "didn't care who made the decisions or what they decided." His further explanation was that this woman, with her illness, had interrupted too many family dinners in the past and he didn't want to be bothered. Verbal consent for surgery had been granted by phone by the brother of the male patient.

When I entered the female patient's room, I introduced myself and asked her if she knew where she was. She was aware of her surroundings and explained to me that she had fallen, her hip was broken, she was in pain and she was hungry. She understood the risks involved in the operation and what would happen to her if she did not have the surgery. When I asked why she hadn't eaten the meals delivered to her, she told me that they'd taken her teeth in the emergency room and hadn't returned them. The regular diet they sent required teeth. She was admitted on Saturday morning; I saw her 8 o'clock Sunday night. All she had furnished her at that point were meals she wasn't able to eat and water.

I asked why she'd not raised this with the staff, she explained they had not addressed her directly since her admission but rather came in, did their care duties, sometimes two at a time, never spoke to her, but rather over her to each other. She had not received any medication for pain since her admission. She was not surprised that her brother had refused consent on behalf of her surgery—the relationship had not been close for many years—but was annoyed that she had not been asked for consent herself. She explained, "I have schizophrenia; I'm not stupid." When I questioned her about why she had not spoken to the staff since her admission, she explained that after so many years of institutionalized care she'd learned not to rock the boat and never volunteer information without being asked for it. No one had asked her anything and, anyway, she was embarrassed to talk without her teeth.

I explained the public guardian and trustee would give consent on her behalf and she was relieved that the



surgery would not be delayed. I informed the patient that she could speak up to staff if she had a problem or a question, but she feared that she wouldn't be listened to. I brought her nurse into the room, introduced her to the patient, and explained to the nurse how the patient feared she would be perceived. The nurse then retrieved the patient's teeth, brought her morphine for the pain, fed her and the patient was grateful to be spoken to, not over or around, and was much more comfortable with the staff situation when I left.

When I visited the male patient, I was met with very similar circumstances. He knew what had happened to him, why he was there, but wasn't sure what hospital he was in because nobody had bothered to tell him. He had not been spoken to directly by staff either, but they'd spoonfed him his meals. He had not received any pain medication. He was offended by the idea that his brother had been given authority to act on his behalf for decision-making without his being asked or informed, since according to him he hadn't received as much as a Christmas card from him for over the last five years. He also understood the implications of the surgery; so well in fact, he said he hoped he wouldn't die of pneumonia in recovery, because he knew others who had suffered that fate. Again, I brought staff into the room, introduced them to their patient, and filled out the appropriate forms.

The staff were incredulous that the patients had spoken at all. They'd assumed that patients, due to their psychiatric diagnosis, were unable to communicate. This is not a new hospital. This is not a new program. These are osteopathic nurses in a well-known, well-respected setting.

This situation illustrated to me there are serious deficiencies in the health care system in that, firstly, nursing staff felt justified in treating patients with disrespect because of the stigmas attached to mental health problems. These professionals were, to a person, totally dismissive of the idea of self-determination or independence for either of these people. Fear and ignorance in general society means that discrimination and isolation are daily realities for many vulnerable people. These are particularly disempowering and painful when these realities are encountered in a health and social service setting. I don't believe the outcome of either of these cases, the surgeries, would have changed if they'd not received independent rights advice. It wouldn't have mattered if they'd received it at all, but I know both patients felt much more honoured for having been considered.

An elderly male patient who had suffered a debilitating stroke here in Windsor was made incapable of financial management when the hospital staff realized his niece was helping herself to his money and attempted to have the powers of attorney backdated to predate his incapacity. The public guardian and trustee successfully intercepted the most blatant of these abuses, halting the sale of properties—and I'm talking about considerable property; we're talking about, from what I understood from the records, over \$500,000 worth of property—that she did not have legal right to. It was eventually decided that the niece would be permitted to manage his affairs, as was the patient's wish, but with supervision and with the benefits of the resources of the PG and T, and a management plan was filed.

#### 1150

Early in the new year I was called to give rights advice to a woman who had made a very serious attempt at suicide, and this particular case has direct bearing on the cuts that were made to social service assistance early in the year. I want you to listen to this, because this is just one of many people I've seen in this situation. I know it has nothing to do with this hearing in particular, but it does impact on the number of people who are seeking assistance in the mental health profession as a result of the incredible lack of foresight this government has shown in making indiscriminate cuts to people's funding.

Her financial assistance had been decreased. Her rent was doubled. She couldn't feed or clothe her two teenage sons on what she received. She attempted to go to a local food bank for more food, who after verifying she was on assistance told her she didn't qualify, she made too much on assistance. She decided to approach the local children's aid to have her children put into temporary care so at least they would be fed. The worker informed her there were no spaces for her kids and there was a waiting list for foster care. If it were considered an emergency, however, they would be taken in. When she asked what constituted an emergency, the worker said if anything ever happened to her or she were to die, her kids would be taken in.

She was so desperate to provide food and shelter for her children that she made a very serious attempt on her life. One of her sons ran away, a 15-year-old on the streets in the middle of winter. The other was taken into care. Now she'll have problems retaining the custody of her children because of her psychiatric history. I was able to put her in touch with other community agencies that helped to some degree.

The next circumstance I'm going to describe is one that is a very personal one that affected me before this legislation was put in place. A personal experience of just over a year ago clearly illustrated for me the necessity of the provision of mandatory rights advice to ensure that previously expressed wishes for care are taken into account when a person becomes incapable.

One of my closest friends of many years, a 42-year-old man, had AIDS. I cared for him on several occasions after hospitalization for serious complications due to the progression of his disease. This is an intelligent, prosperous, independent man who had worked for AIDS service organizations for years before he became too ill. He was sadly acquainted with how some families behave when people with AIDS become ill and prepared well in advance to avoid the circumstances that had caused so much stress in other people's lives.

He had made clear, concise requests in writing about how he wished to be cared for if he became too ill to manage on his own, asking his ex-partner and myself to share the responsibility of health care decisions together and financial and property management to be handled by a third friend. His motivation for these decisions was the fact that he'd been estranged from his family for decades and although he wanted to spend time with them before he died, he did not want them influencing his care decisions.



Both his partner and I have extensive experience working with persons with AIDS and his fundamentalist Christian parents were ashamed of him and his disease and chose not to educate themselves about it. He wanted to heal the strained relationship before his death and to appease his family agreed to move to their home town with the understanding that they would contact us as soon as it became necessary. Now, this was acknowledged personally face to face as well as in writing.

Instead what happened was the exact situation my friend tried to avoid. His parents did not contact us when he became ill and waited until 12 hours before he died to bother. In the meantime, the last 10 days of his life, they allowed him to be subjected to numerous invasive procedures that he'd expressly wished to avoid, including the administration of medications that had been toxic in the past to him, unnecessary biopsies, even though he clearly repeatedly protested the proposed treatments. Instead of allowing their son the gentle passing we'd pledged to give him, in their panic and fear they made his last days on earth a living hell.

Within a day of his death they had gone to his home and destroyed everything that could be associated with any aspect of his life that they didn't approve of, including photographs and journals that had been prepared to be published. The people who loved him, his family of choice, who had been entrusted to his care were not acknowledged by either the health care professionals nor his family. They did not present the powers of attorney that had been drawn up when their son was well and able and they interceded when we tried to contact him. A formal process providing rights advice would have saved my friend untold pain and the friends who loved him untold guilt and sorrow.

These anecdotes are just a few of the incidences that I've experienced since beginning my employment with the commission. A lot of equally horrific things have occurred that I've been witness to in my work as a volunteer with other organizations.

Misconceptions about rights advice abound. I do not—I repeat, I do not—ever make decisions for anyone. I merely present them with the information they require to make the choices they need to make and I enable them to participate in making these decisions. A lot of what I do is active listening, something there is little time for in the psychiatric setting in particular.

In the Windsor-Essex county area, the average psychiatrist spends a total of three minutes per day with a hospitalized patient. This is someone who has been stripped of their rights who is hospitalized. Don't forget, I only see the people who have been put on forms. I don't see everyone who has an admission. You'd have to have 10 or 15 of me. I only see the people whose rights have been taken away from them by a psychiatrist or a medical practitioner. I don't see anyone else. I'm only in to see people whom I'm called in to see.

We have 15 psychiatrists in this area. We need 35 to keep up with the caseload. Rights advice provides patients with a feeling of value and wellbeing. They realize I'm there exclusively to represent their interests. Most often patients determine that they are in the right

place, their doctor is making the right decisions for their care. Sometimes they just need that reassurance.

I do not become embroiled in family situations unless the vulnerable person is left out of the decision-making loop. Most families welcome a clear understanding of the legislation and value the autonomy of their elders and those who are ill. They work towards solutions and do not see this legislation as problematic or the services as invasive. Over 500 visits and I've only had two incidences that a family became upset about their member being given rights advice. Both of these people thought that—one was a young woman whose mother didn't want me to give rights advice because there was a situation of abuse in the family that she was afraid this young woman was going to disclose. The second was an elderly woman whose daughters didn't want her to know that she had rights to contest some of the decisions that were being made around her care.

There has not been one single formal complaint about the provision of rights advice service since the implementation of rights advice in this province under the Advocacy Commission. Very few misunderstandings have occurred. These have been resolved quickly and creatively.

I would like to submit some concerns I have about the proposed changes of this legislation in Bill 19 that I feel will seriously undermine the gains made by vulnerable people since the proclamation.

The proposed reconfiguration of the Consent and Capacity Review Board which allows the chair to name one person to act on his behalf to hear cases is totally disempowering to people who are in need, absolutely. They are being told they're being locked up by one person. They want a panel to hear them, and they should be entitled to have people making a decision around the information that have some skill in capacity assessment, not someone who isn't clued into what's going on.

The provision of protection from liability for decisions made by substitute decision-makers and health practitioners around treatment or admission to a facility further disempowers the vulnerable. We aren't in Ontario a litigious society by nature, although I can see a lot of charter challenges coming up. To remove the option of being able to sue your doctor if he does something that is blatantly out of line is tantamount to devaluing and dismissing any value of the patient. In discussion around this issue, several doctors have been dismayed that their less accountable counterparts would be further able to pressure patients without interference or question.

The reintroduction of electric shock therapy for aversive conditioning by a substitute decision-maker is also extremely problematic. I know you've heard People First talk about this, and I can't be more eloquent than they.

The idea that the health practitioner has the right to treat despite refusal, even if the substitute decision-maker is a guardian of the person, attorney for personal care or board-appointed representative, what is the purpose of asking people's consent? If you are told by someone they don't want the treatment, you're told by the substitute decision-maker they don't want the treatment, and the doctor says, "To hell with you, I'm going to give you the treatment anyway," what is the point? There is no value there.



The other issue I want to raise very, very briefly—and there is a summation that is on the last page of this—there are some systemic issues that the Advocacy Commission could really help with. The psychiatrization of youth in Sarnia, for example, is one. I've made numerous calls to Sarnia and very few to Windsor or Chatham; 27 calls to Sarnia so far. Kids who are locked up in psychiatric wards, mostly for behavioural problems—parents can't handle it. Instead of getting help for the parents to learn how to cope with a disgruntled teen, they're putting them in the units and they're locking them up. It's absolutely archaic.

People who are locked up in psychiatric wards—I must preface this; 80% of the people I see are Mental Health Act. The rest of them are consent to treatment and substitute decisions. When people are stripped of their clothes and their dignity and their name—they're given a number—and are given three minutes by their doctor a day, they need to have access to information and care.

I've included in this for your edification, so you do understand that there are health care professionals who do in fact uphold the value of patients receiving rights advice, letters. I'd like to read the names of the people who have sent them, please: Mary Lou Dolan, RN, psychiatric unit manager; Dr R. Frisch, psychologist at the University of Windsor; Mr Harish Carpenter, RN, psychiatric unit manager; Nancy Merry, RN, psychiatric unit manager; Amanda Gellman, executive director of the AIDS Committee of Windsor; Dr P.K. Rai, psychiatrist; Dr Asoka Rajan, psychiatrist; Richard Sabo, mental health planner; and Gary Klein, lawyer.

Had I attempted—

**The Vice-Chair:** Ms Grant-Galli, I am sorry. The 30-minute time allocation has expired. I want to thank you on behalf of the committee for your presentation.

The committee will stand in recess until 1:30.

*The committee recessed from 1202 to 1330.*

SUSAN PHELAN  
NORMA VANDUSER

**The Chair:** Our first submission is from Susan Phelan and Norma VanDuser. Welcome. Please proceed.

**Ms Norma VanDuser:** Mr Chairman and honourable members of the standing committee on administration of justice, I am here today to support the passage of section 66, Bill 19, and I would like to thank you for this opportunity to speak before this committee. I realize that, not being a Canadian citizen, this is most certainly a privilege. However, I am not here as either a Canadian or an American; I am here as a parent who understands the excruciating pain other parents of children with severe self-injuries have had to live with every moment of every day, having been there myself.

I raised my granddaughter, Amber, from birth. She was diagnosed with hydrocephalus, which required the implantation of a shunt to drain the fluid from the brain. She also engaged in self-injury at the early age of 18 months. The most serious of her self-injurious behaviours had been head-banging, including head to table, head to floor, knee to head and hand to head. The intensity of these behaviours had reached such severity that they were causing dreadful damage that included black, swollen

eyes, a broken and bloody nose, a concussion with a perforated eardrum, and eventually brain damage. She had also begun to aim her blow to the head directly at her shunt implant, a behaviour we and her neurologist considered life-threatening due to the danger of dislodging or damaging the shunt itself.

We had reached the point where I had found myself actually sleeping with my arms wrapped around her every night in order to prevent her from either hitting herself with her fist or slamming her head against the bed, as she had the night she received the concussion. Now the days and nights seemed to run together, and the only hope left was medication or restraints.

Reluctantly, we tried medications. The medications we tried had to be increased to the point where they were nothing less than a chemical lobotomy. We wanted more than a vegetative state for Amber. Restraint would have to be constant, resulting in essentially the same inability to function as the medication produced.

Then, on a visit to her neurologist, he talked to me about a new aversive treatment, faradaic skin-shock. He gave me some literature and a videotape to take home. Almost two years later, at the age of seven, after a lot of agonizing and her injuries mounting up, we decided that this was her last hope, a treatment of last resort.

We were absolutely astounded by the immediate results. Amber's rates before the aversive treatment were 30 to 40 hits per minute. Two days after implementing this treatment, Amber's rates of head-banging dropped to relatively zero. Within two months, Amber began walking with a walker, communicating more and, especially delightful to us, she was full of giggles, hugs and kisses—not at all that frustrated, unhappy little girl we knew before.

Amber utilized this treatment for almost four years. Her rates of head-banging remained at near zero. The treatment was no longer needed at home. Progress on all fronts had been made. She developed a good vocabulary of both expressive and receptive language. She could recognize words that were spelled out verbally to her and was just beginning to recognize written letters and small words. Best of all, she could now say, "I love you," words I never thought I would hear. She was a remarkable and courageous child.

Unfortunately, we lost Amber to medical complications unrelated to her self-injury. However, thanks to this treatment, we were able to experience the love that Amber was finally able to express to us and we cherish the remarkable memories that were made during the years she utilized this treatment.

I don't know what we as parents can say that will prevent interference from those who have not experienced the pain that families who have children with self-injury have gone through and the gift of hope and the gift of joy in watching their child become a real participant in life. During Amber's nearly four years of treatment we experienced a lot of interference and attempts to remove the aversive treatment. We were not only fighting to keep her alive and well, but we had to go to court and fight to keep the very treatment that was saving her life and allowing her to remain at home with those of us who loved her.

Some people do not hear our voices. Perhaps you have the answer to that dilemma in your hands in the form of this proposed Bill 19. Please consider carefully the lives of the children and adults afflicted with self-injury before you make your decision. I urge you to pass this bill.

Thank you again for allowing me to speak to you today on this important subject.

There's one other thing I wanted to say. In 1989, Amber was the first one in Michigan to receive this treatment, and since then there have only been two other cases. I want you to understand: People do not line up around the block to get this treatment; it's only for those children who really need it.

**Ms Susan Phelan:** Chairman and honourable members of the standing committee on administration of justice, I also am here today to support the passage of Bill 19, section 66, and wish to thank you for this opportunity to speak.

Like Ms Van Duser, I am not here as a voice representing any of the many advocacy groups that speak on behalf of disabled people in general, but as the parent of a severely self-injurious child who has not been successfully treated through the use of medications and non-aversive techniques alone, whose voice I hope will convey the necessity for preserving the availability of the treatment of faradaic skin-shock as a lifesaving treatment for those in desperate need of protection.

When my son was born 21 years ago he suffered severe birth trauma. Due to the high-forceps procedure used in his delivery and the misplacing of the forceps, he had no respiration, no muscle tone, no reflexes, and his heartbeat was critically low. When I first saw him a few hours later, his face was misshapen, swollen, battered and bruised. He had a black eye that took almost six months to fade away completely. I was told that this and the resulting damage to his eye were due to the misplacing of the forceps, but now I wonder if he could have been self-injurious in the womb.

Terry started to receive therapy when he was three months old. By the time he was a little more than a year, he had made some improvements physically, could roll over but not crawl, could sit in a corner chair but not sit independently, was wearing glasses, refused to drink from the bottle and had no interest in learning how to drink from a cup or finger-feeding, would handle toys for only a few seconds before throwing them away, had suffered ear infections and had started banging his head against the rails of his crib.

By the time he entered school at the age of three, his head-banging behaviour had progressed to his hitting himself in the head with his fists. He had been attending OT, PT and speech therapy regularly. Sensory integration therapy had been the main focus to deal with his tactile defensiveness behaviour. He seemed irritated with touching around his mouth, head and extremities. I sent him to school with a toy truck in his hand to keep it occupied during transportation, which worked for a while. Soon, the school recommended the use of a protective helmet, which worked until Terry realized the helmet had pie-shaped holes on the top through which he could hit his head. For a short time we tried padding his right hand, but that interfered with his ability to learn to feed

himself and play with toys, so a football helmet was prescribed.

By age five he had made no gains in receptive or expressive language for eight months and his self-abusive behaviour had increased to the point to where he could now hit himself on the chin underneath the helmet and was starting to kick himself in the head with his feet.

**1340**

While the teacher and everyone else working with Terry at the school were encouraging me by saying they could see a lot of potential, but his behaviour kept getting in the way, and that he probably should be in a trainable mentally impaired classroom instead of the severely mentally impaired classroom he was in, if it weren't for his behaviour problems, at the same time the social worker at the hospital was trying to convince me I had unrealistic expectations and the physical therapist there felt he would be "more trouble" if he learned to walk. When I asked the many doctors involved with his care for help, they said, "Kids like him do that."

One night, while using a Pringles potato chip can on his arm as a splint, I awoke to the well-known thump, thump, thump coming from his bedroom. I ran in and found Terry's face and pillow covered in blood. He had learned how to remove the can. His eyes were swollen shut. When I grabbed his arm to stop him, he started to cry and so did I. I cleaned him up and took him to the emergency room. While there, a young nurse's aide—and I'm sure from the looks, many others—thought I had abused my son.

I sought out the help of a private psychologist to evaluate Terry's current school placement. He assured me that his placement in the SMI classroom was appropriate due to his behaviour problems. He said that he saw the early signs of severe self-injurious behaviour, and although there were some medications that might be helpful, he warned me of their side effects and the fact that he might need a dosage strong enough to control the behaviour that would hinder his ability to learn.

Then he continued, to tell me about contingent electrical stimulation, CES. He told me it would work and how I would go about using it if I chose to. He told me about the cattle prod, how it worked with cattle, and how I would have to get the device and use it on my son, around age 7 at the time, and how I would have to use it in my own home, "behind closed doors," without the help of school or any other professionals because it was a controversial treatment. He said he wasn't recommending it, but that due to the severity of Terry's behaviour, he felt it was his duty to inform me. He said it was so controversial that if I told anyone that he told me about it, he would deny he had told me.

I chose at that time to continue with non-aversive approaches, restraint, and psychological consultation for myself. As the years passed, we tried various restraints, behaviour modification techniques and some medications. It was during our trial of Haldol that Terry experienced an increase in seizures. He had one seizure every three minutes or less. While weaning him off the Haldol, his neurologist suggested we continue down the list of drugs till we found one that worked. He said if we didn't find one that worked, the only other answer would be sur-



gery—lobotomy. I was devastated. I felt sick to my stomach and I didn't know where to turn.

Two months later, a friend of mine showed me an article about Amber and the use of the SIBIS in our local paper. I immediately called information and thank God Norma had her number listed. As she described Amber and her behaviours, I started to cry. Finally, I had found someone who knew at first hand what we had been going through. As she described Amber's behaviour, it brought back memories of what Terry was like at that age. I thought of what she had in store for her future if this treatment didn't work and I thought of what Terry's life could have been like now if this would have been available to him at that age.

After seeing the success with Amber, I sought to secure the treatment for Terry. Due to the interference of advocate groups in my area, it took me three years to secure this treatment for him, and I had to send him 800 miles away to get it.

I am happy to report that the use of the treatment helped get his behaviours under control enough for doctors to find and diagnose a medical condition that probably contributed to his behaviours, which has since been successfully surgically corrected. Unfortunately, through the years of self-abuse and his increasing strength, he has lost the vision in one of his eyes.

He still uses the treatment and some restraints, but to a much lesser degree. When he went to the Judge Rotenberg Educational Center, he was in four-point restraints, in a wheelchair, and wearing a hard-shell helmet with a full faceguard, and still doing chin to shoulder. Without these restraints, he would hit his head at the rate of 124 hits per minute and would exhibit other behaviours, such as head to knee, head to table or doorway, head to floor, finger pokes to the eye, chin to shoulder, kicking himself, biting himself and hitting and head-butting others with his helmet. Now he wears a wrist strap that we've been able to extend to eight inches so far—we hope to be able to eliminate this completely some day—a soft-shell helmet with a partial faceguard and a device similar to the device being used with Brian Singer in Dr Barrera's care in Blenheim. He receives an average of about four or five shocks per month. He is happy, healthy and finally learning to communicate with a voice output communication device. When I visit him, we enjoy going places and doing things. We go to restaurants, malls, whale watches, festivals, concerts and movie theatres. He will be returning home some time this year, and I'm looking forward to having him back in his own home.

I believe that many who could benefit from the use of CES are being physically or chemically restrained and that some have unfortunately already died from the injuries they have caused to themselves or the side effects of medications. If they cannot control their life-threatening behaviours themselves, then it is our duty to find a way that does not further risk their health or life. The number of people needing this form of treatment is very small, but that doesn't matter. If it was needed for only one person in the whole country, and that one person was your loved one, you wouldn't want someone to make it unavailable as a life-saving treatment option.

Thank you for letting us share our true stories about our loved ones with you. As your neighbours, we ask that you please consider the lives of our friends in Canada who would be affected by this legislation and vote to pass Bill 19.

**Mr David Ramsay (Timiskaming):** I'd like to thank the two presenters for taking the time to come before us, especially when you come to our jurisdiction to offer your suggestions and advice. The personal histories that you've outlined I think really bring it home to us that regardless of how repugnant certain treatments might at first hand appear, I truly believe we should never rule out anything that in the end might be the answer, even if it's only for a few. I support you in that belief and certainly will be supporting this part of the legislation.

**Ms VanDuser:** Thank you.

**Mrs Boyd:** Thank you very much. I should tell you that the literature and many of the testimonies of parents like you have been taken into account in terms of the previous legislation. I wouldn't want you to think that legislation forbade the treatment without a whole lot of concern around those kinds of issues. But you have admitted, both of you, in your presentations, that the concern is overwhelming in terms of this treatment and that many jurisdictions have taken the position that this jurisdiction has taken up until this point.

What I would ask you, as I asked the parents this morning: Since you are of the belief that this would only be a limited number of cases, would you think that going to the courts ahead of time and getting the permission to do this treatment, showing that in fact everything else had been tried and this was one of those very strange cases that couldn't be dealt with any other way, would be the appropriate way to do it, particularly if it could be done without the kind of cost to parents that we've heard from both your presentation and the presentation earlier this morning?

1350

**Ms VanDuser:** Cost would be a concern to me because there are a lot of parents who could not afford an attorney. I don't know about courts, whether that's the appropriate—

**Mr Boyd:** Or a capacity board. Either one, whatever mechanism we determined.

**Ms VanDuser:** We have a behaviour review committee, peer review and a human rights committee that approves or disapproves, and at that point, if, for example, they were all to turn the parents down in their request for this treatment, then the parents have an option at that time to go to court.

I'm not opposed to a check and balance system. I think you have to be very careful about that system. For example, Amber had a shunt. She did not have the time to go through some lengthy process. The reason it took us two years wasn't just thinking about it. We thought about it day and night. But we had to get into my husband's retirement in order to purchase the device, because it wasn't medically insured. But she really didn't have two years. She did a lot of damage during those two years that we could never get back. So I think you have to look at, if you're going to set up a review committee, the length of time.

**Mrs Boyd:** Timeliness is important.

**Ms VanDuser:** And emergency cases maybe would be an exception where you would have emergency meetings.

**Ms Phelan:** Like I said in my speech, it took me three years from the time I requested it to finally get it as a treatment in my son's program. During that three years, he did more damage and he has now lost the sight in one of his eyes. I think you have to really weigh what is an emergency and have provisions for that.

But certainly it should have to go through some sort of a review. It shouldn't just be available for just anyone. It has to be regulated.

**Mr Klees:** Thank you very much for your presentation. As you know, in the context of these hearings, we're discussing the issue of advocacy. I just want to thank you, just the fact that it's so very obvious that people like yourselves are willing to take the time to advocate on behalf of others who might find themselves in the same situation that you do. This bill certainly will solve the problem that you faced and that others have in our jurisdiction, because it does provide for the removal of the prohibition.

We are interested in ensuring that this treatment is administered in a safe way. So the questions that are being put to you are really for the purpose of ensuring that we do administer this in the safest way possible. From all the submissions we've heard, not one didn't go to every length possible to find other ways of dealing with the problem. As you say, people don't seem to be lining up to be using this or to have it used as a treatment. So the very practical things that we're trying to get a sense of is, how can we put the safeguards in place but at the same time make sure that we don't put people through unnecessary waiting periods, because it's obviously difficult on families, more importantly on the children themselves?

This has been very helpful, and what I hear from you is that you feel that certainly there should be some professional guidance, perhaps some restrictions in terms of ensuring that the proper assessment has been made, and only then should this treatment be applied.

Just in terms of again perhaps a practical recommendation that you might have for us, given your circumstances, what do you feel the process should have been that would have allowed you to go to this form of treatment in terms of the—go ahead.

**Ms VanDuser:** I think the committees we talked about, I don't know if you'd call them the same thing, but we had the behaviour review committee, which was staffed—and the parent was a member of every committee. But it was staffed by, say, school personnel, if the person's in school, someone from an institution. There were advocates also on the panel. It was basically made up of a variety of people from the community. The peer review was parents, parents of other children. The human rights committee was made up of a lot of the—like the behaviour management committee, it was various numbers of people.

I think it's also important, again, when you talk about the committee aspect when we talk about the emergency situation—and it was mentioned earlier about trying

everything first. There are thousands of behavioural methods out there, and some children don't have time to go through every one of them. So I think that also has to be taken into consideration.

**Mr Klees:** Thank you very much. Again, thank you for taking the time to be here with us today.

**Ms Phelan:** Thank you for having us.

**The Chair:** Thank you very much again, Susan, Norma. We really appreciate your attending today.

**Ms VanDuser:** Thank you for letting us be here.

#### ASSOCIATION OF THE PHYSICALLY HANDICAPPED, WINDSOR AND ESSEX COUNTY

**The Chair:** The 2 o'clock submission, the Association of the Physically Handicapped, I believe it's a Mr Ralph Evans and a Katherine Webster. Welcome, Mr Evans and Ms Webster. Get settled. We've got time.

**Mr Ralph Evans:** We have arrived.

**The Chair:** Could we just make sure of the name of your association. Is it the Association of the Physically Handicapped?

**Ms Katherine Webster:** Yes, that is correct.

**The Chair:** Is there no geographical description?

**Ms Webster:** It is Windsor and Essex county association.

**The Chair:** Fine. Thank you. You may proceed.

**Mr Evans:** I must apologize first for not having any brief for the committee. Due to miscommunication, I didn't get the confirming letter of my time and date to speak, so I wasn't expecting to be here.

First of all, I'd like to introduce Katherine Webster, the executive director of APH. My name is Ralph Evans, and I'm a member of that organization. My disability is amyotrophic lateral sclerosis. I've had it for 14 years but I'm not confined to it. I am, as of right now, perfectly able and capable of making my wishes known to anyone with regard to my personal care, to my treatment, to any surgery that I may require. I do know that at some point in time, that communication skill, that being able to verbalize what my wishes are, is not going to be there.

The Advocacy Act, as it was—and I know it is going to be repealed—would have given me some way in which to make my wishes known should I require any kind of procedure in a hospital, any of my rights.

It could come out that it could be said to me, "Well, you can do that in a living will." I am not convinced at this moment in time that the specialist standing at my bed in hospital is going to take the time to go down to my safety deposit box to get my living will to find out what my wishes are with regard to any of the treatments, since his bottom line is that he wants an answer now.

Being able to communicate my wishes through an advocate, be it a family member or a friend—and I must point out that all my family is in England, so that removes one aspect of my being able to communicate except to a friend. I would still like to see the act in place, even though it may need to be changed in some areas. But that act at least gave me some ways in which my wishes on my rights could be communicated through another person should I become incapable.



1400

I'm talking off the top of my head here. I can't think of anything else that I need to say, so I'll try to do my best to answer any questions. Unless Katherine wants to say anything.

**The Chair:** Is there any submission you'd like to make, Mrs Webster?

**Ms Webster:** No, thank you.

**The Chair:** Okay. We have a considerable length of time, for the first time in history, I think, on this committee. I can't even calculate it. I usually don't go over five minutes, but you've got at least eight minutes.

**Mrs Boyd:** I'm very pleased to have an opportunity to talk to you a little bit about some of the concerns you have. I just need to be sure that I realize exactly where your concern lies. You do understand that you're able to name a substitute decision-maker and that you're able to have a power of attorney for personal care and that you're able to leave fairly detailed instructions about what you would want or not want to be done. Your concern is that you have no confidence that the professionals would necessarily make the effort to contact that person and to carry through.

**Mr Evans:** That's correct.

**Mrs Boyd:** You felt the advocates that were set up under the Advocacy Act were sort of your assurance that at that point in time your rights would be respected.

**Mr Evans:** Right, yes.

**Mrs Boyd:** In terms of that whole area, over the last number of years, you must have had quite a variety of experiences with professionals and have some sense of why you have that lack of confidence. Have you any way that you would like to talk to us a little bit about what it is, whether it's the time constraints or the resource constraints, the professional attitudes or whatever it is that gives rise to your lack of confidence the professionals would honour that?

**Mr Evans:** I have to say that I do have faith in the specialist and the physicians who look after me, but since they are not around me—and I wouldn't say 24 hours a day, because that's an impossibility, but they are not around me adequately enough, I feel, to really get to know what my wishes are with regard to treatment. A personal friend or a family member would at least get to know me and would know the underlying source. I cannot ever envisage a situation where a specialist has come to me saying, "This is the treatment we need to do. Yes or no?" and then taking the time to hear what my wishes are. Even though they may be written down at some other point, in a safety deposit box or with a friend, I really don't think they're going to take that time to get that. Unless I carry all that information around with me in my chair, it's never going to get known to anyone other than my friends.

**Mrs Boyd:** Because although you have a condition that causes a fairly regular deterioration, there can be sudden changes, can't there, because of the various complications that can arise?

**Mr Evans:** Yes.

**Mrs Boyd:** So you're worried about the emergency provisions, I expect, and whether that would then respect your wishes.

**Mr Evans:** Absolutely.

**Mrs Boyd:** Several people have expressed that real concern that in an emergency situation—and many people with varying forms of disabilities can face an emergency that may or may not have anything to do with a disability—those wishes might not be respected. So do you share the concern that's been expressed to us that physicians ought not to be able to override unless their patient has had an opportunity to know their rights?

**Mr Evans:** Absolutely, yes.

**Mrs Boyd:** Do you have a sense that even the rights advisers as they have existed, because of course the advocacy part never got started, have been able to form some of that function, just the very fact that there has to be the pause and then the person to talk to?

**Mr Evans:** Yes. I was quite amazed. I strongly feel that the hearings should have been had first and then a decision made as to whether they should repeal the Advocacy Act. Don't repeal it first and then have hearings, because with the way the government has done it, they're not going to change their mind on what they have already said they're going to do. So I don't feel in any way confident at all that anything is going to be heard; I really don't.

**Mrs Boyd:** The concern we have is that there were very extensive hearings and very many years of study and a number of reports prior to the institution of the Advocacy Act.

**Mr Evans:** The O'Sullivan report is one that comes to mind.

**Mrs Boyd:** Sure. I guess you're very fortunate that you have friends you want to name and can trust, but I expect you know of lots of people who don't have that luxury and really, really need to know that there will be some official available to them under those circumstances.

**Mr Evans:** Yes, ma'am.

**Mr Marchese:** I wanted to simply say that we agree with the point that you're making. A number of people this morning have spoken, including Mr La Bute, who talked about, in his words more or less, that December 10, 1992, when we set up or proclaimed the Advocacy Act and the commission, was a day of reckoning for him—and many others, I suspect—that he felt that he was given an equal status now and that they were now on a level playing field. People felt that with that commission they were inside and not on the outside and less marginalized.

Other people this morning—the Citizen Advocacy Windsor-Essex group—talked about why we need this commission, why we need rights advisers, because they talked about their own limitations to be able to do things. They said that family and friends sometimes create the need for their support. They said that they don't have the authority to intervene often in a lot of cases to be able to deal with some of the abuses. Those associations that are there to serve people like yourself are not able to deal with those issues because they don't have the authority.

Without the authority, how can the government say, which is what they've been saying for weeks: "We want advocacy. We want somebody else to do it, but not the government. Everybody should have a responsibility for

advocacy"? Although I think that's wonderful to say, if the government abrogates its own responsibility for advocacy, who's going to do it? It doesn't happen simply because government members are saying, "Well, we all have a responsibility."

I'm a bit frightened about these things, that, as they say, they will simply happen and that government should be out of the way of these things, that rights advisers were too interfering and that it's too costly a service. I disagree with them and I suspect you do too.

**Mr Evans:** I can remember, and I may be wrong in my numbers, that the Advocacy Act, the Substitute Decisions Act and the Consent to Treatment Act didn't arrive overnight. I can remember many, many years of heated debate. Is that polite way of putting it?

**Mrs Boyd:** Free and frank discussion.

**Mr Evans:** It just seems like overnight the government of the day has said, "We don't want it," without going back to at least those people who had input into it and asking, "Where can we change it?" first. Then, if they choose to do so, repeal the act afterwards. But it wasn't that bad that it had to be gotten rid of.

**Mr Marchese:** You're quite right, and although a number of people told us it wasn't a perfect commission, we realized that was the forum for us to be able to raise issues. We rallied around it. Yes, we could have improved it, and if it was too costly, yes, the government could have chopped that down but still allowed the commission to work in some form that would allow you some satisfaction.

**Mr Evans:** I can remember the fight between changing from a schedule 1 to a schedule 3.

**Mrs Boyd:** A very good fight.

**Mr Evans:** Yes.

**Mr Gary L. Leadston (Kitchener-Wilmot):** I appreciate the opportunity to ask some questions. Mr Evans, I assume that you've been a resident of Windsor-Essex for some time. I'm rather curious to know who would have advocated for you prior to the legislation being enacted in terms of your concerns that you've expressed this afternoon.

**Mr Evans:** As you can feel, I would have advocated for myself. I am quite able to do that on my own with the rights that were available to me at that time. I know that I can make my wishes known, as I've said, through a power of attorney or through a living will, but I don't think those would be made available to the physician standing at my bedside saying: "We have this treatment to do. Yes or no, do you want it?"

1410

**Mr Leadston:** Again, I make an assumption that you would have a family physician who's familiar with your health and your condition. Should he not be aware of your concerns and your desires in terms of treatment?

**Mr Evans:** He should be concerned surrounding my disability, but I think the underlying essence that goes along with the decisions I make should be made through someone outside of a physician, either a family member—as I say, mine are all in England, so it's got to be through a friend. I can speak more openly to them with regard to what I need. I don't think a family physician or

a specialist is going to take time enough to listen to my reasoning as to why I would want or not want treatment.

**Mr Leadston:** Thank you for your openness and your frankness this afternoon. It's been enlightening.

**Mr Evans:** Thank you, sir.

**Mr Klees:** I'd like to just take a minute to perhaps clarify a matter. I think you expressed some concern that a doctor may override your personal wishes in the event of emergency treatment and your concern that there isn't some safeguard in place for you with regard to that. Is that correct?

**Mr Evans:** That's correct.

**Mr Klees:** I'd like to point you to section 24 of the Health Care Consent Act, which says—and I think we've got the time—"A health practitioner shall not administer a treatment under section 23 if the health practitioner has reasonable grounds to believe that the person, while capable and after attaining 16 years of age, expressed a wish applicable to the circumstances to refuse consent to the treatment." So there is a strong indication here, provision within the legislation that no treatment contrary to your wishes should be provided to you.

**Mr Evans:** But that's only if I can express that wish.

**Mr Klees:** Section 25 then goes on to deal with your other concern, and that is that, "If consent to a treatment is refused on an incapable person's behalf"—in other words, by your substitute decision-maker—"the treatment may be administered despite the refusal if, in the opinion of the health practitioner proposing the treatment," first of all, "there is an emergency." I'm assuming that if there was an emergency, you don't have a problem with the health practitioner saving your life or administering a treatment that, in his professional opinion, is in your best interest. Do I assume that correctly?

**Mr Evans:** He has the perfect right under the Hippocratic oath to preserve and save my life to the best of his abilities, but if he's performing a treatment or a procedure on me that I have already expressed elsewhere I don't want, and if I cannot adequately express that—my disability at some point in time is going to take away my ability to speak—then if I am in an emergency room and I can't adequately express my wishes even to say that my wishes are known elsewhere, then how is he going to know what my wishes are unless I can communicate that through an advocate? I really don't think he's going to take that time to find out who my advocate is or whom I've expressed my wishes to.

**Mr Klees:** You've certainly touched on a practical point here. The fact is that the legislation does protect you, though, to the extent that the health practitioner has the authority under this legislation—and in fact, as you indicated, under his professional code the responsibility—to administer emergency treatment. If, however, he is aware that there are instructions elsewhere, there's very express obligation on the part of this legislation that he find that person and get instructions accordingly. That's very clearly expressed in this legislation.

I wanted to clarify that for you because I think the concern you are addressing—whether there is a formal rights advocate in place or whether it's a family member or a friend you've designated as a substitute decision-maker—isn't the issue, because if the doctor can't find



that person, it doesn't matter if we're paying \$18 million to a horde of people to come to your aid if we can't find them. So I think the essence of your concern is addressed in the legislation and I just wanted to clarify that for you.

The other point I want to make: It distresses me somewhat when I hear my friend, Mr Marchese, repeatedly make the statement in this committee that the government is setting aside advocacy and suggests that because we're not implementing an act, because we're repealing an act, we don't care and that advocacy is not important us. For the record, I want to state this again very clearly: We believe vulnerable people need assistance. However, we cannot afford \$18 million at this time to provide the kind of bureaucratic structure that the previous government intended. In fact, in these discussions—

**Mrs Boyd:** A tax cut.

**Mr Klees:** —we have heard even Mrs Boyd make the statement that there are some things with that previous act that don't work very well. I think what's important is that people like yourself have the strong assurance from our government that we care very much about advocacy, that we support it, that we want to find the most effective and cost-effective way of delivering that and ensuring you're supported.

We happen to believe differently. The previous government believed that with every problem you could solve it with money. We happen, philosophically and practically, to disagree with that position. We happen to believe there are effective ways of providing advocacy that will not cost the kind of money, that will not be as time-consuming and bureaucratic as the previous Advocacy Act provided, and we will be pleased to work with you.

**Mr Evans:** Could I just ask a question?

**Mr Klees:** Sure.

**Mr Ramsay:** You're being lectured to right now.

**Mr Klees:** It's lecturing when I do it and when you do it, it's consulting. Let's be serious about why we're here. We're here to listen to these people.

**The Chair:** Thank you, Mr Klees. I think Mr Evans did have a point.

**Mr Evans:** With the \$18 million aside, what specifically was wrong with the Advocacy Act that the whole thing had to be shelved?

**Mr Klees:** It was all based on a premise that family, friends were inadequate and that government could provide, and in fact government is the only source of advocacy. That was the premise.

**Mr Evans:** Your government said to us in regard to day care that family and friends should be the ones to look after those children when the parents need to go to work, and now you're saying on the other side of the coin, that family and friends have no business in advocacy.

**Mr Klees:** No, to the contrary. We're saying that family and friends should in fact play the leading role in advocacy and what I was saying was the previous government—

**Mr Evans:** But if that was in the Advocacy Act, why get rid of it then?

**Mr Klees:** We're saying it wasn't in the act. The previous act precluded families and friends—

**Mrs Boyd:** It did not. That's not true.

**Mr Klees:** It put government ahead of family and friends in the process. That was the issue.

*Interjections.*

**The Chair:** Mr Klees and Mr Evans, this has been great, but unfortunately the time is up for the government caucus, and now Mr Duncan will be summing up for us.

**Mr Duncan:** Thank you for the direction.

**Mrs Boyd:** He's got eight minutes to do it in, though, doesn't he, Mr Chair?

**The Chair:** He has nine minutes.

**Mr Duncan:** I have nine minutes. I don't want to engage in the kind of discussion I just heard.

I want to thank you for your presentation. Your thoughts are obviously very well put, and as always, your organization is thoughtful and comes at this with genuine interest and deserves to be accorded a certain amount of respect for your views.

As you know, we spoke at length during the election. I think I spoke with your group about our views on the Advocacy Act and our view that we felt there was need for change. We have some accord with a number of things that are contained in Bill 19; there are some problems with it. We've heard delegations throughout the province that have made a number of recommendations to us and we will take those to heart.

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Our view, however, and it's been reinforced to me—I've just been with this committee for one week; I'm subbing for another member—is that in fact there are people who do need advocacy beyond a pat on the back and, "We support advocacy," and, "Rah, rah, rah." They're cutting now. They'll shut it down. My guess is you won't hear from them again. I think you know that and I think the people in the field know that as to this nonsense about, "Oh, we're going to talk more about it," if they wanted to talk more about it, they would have done something about it and proposed an alternative in the legislation they brought forward. To suggest somehow that you're going to hear from them again, well, we'll see. Maybe we can convene a hearing down here and can invite these members down here to discuss alternatives. We've done that before.

Thank you for your presentation. I appreciate it and please stay in touch with us in the weeks and months to come as we look for alternatives.

**Mr Evans:** Thank you, Mr Chair, for the opportunity.

**The Chair:** Not at all. Thank you for coming today, Mr Evans, Ms Webster.

**Mr Klees:** Mr Chairman, do we still have some time?

**The Chair:** No. Well, not you, I'm sorry.

**Mr Duncan:** I'm not yielding the floor to someone else.

**The Chair:** Each person gets an equal amount of time whether he uses it or not.

**Mr Klees:** Why don't we ask for some practical suggestions? We've got some more time.

**Mr Duncan:** We'll set up some special hearings and if you're interested in coming down, you can come down. You just said—

**Mr Klees:** We're here now.

**Mr Clement:** We're here now.

**Mr Duncan:** No, you've got a bill here that doesn't deal with advocacy. What we've got here cancels advocacy. You're the government. You propose, we dispose. You're silent on advocacy.

**The Chair:** Excuse me, I have the floor, just for a moment. I thank you, Mr Evans. We will proceed to our next submission.

**Mr Evans:** Have a good day, sir.

CANADIAN MENTAL HEALTH ASSOCIATION,  
WINDSOR-ESSEX COUNTY BRANCH

**The Chair:** The Canadian Mental Health Association, Windsor-Essex, Pay Hayward and Vince Carruthers. We have one half-hour allocated to your submission.

**Ms Pat Hayward:** I'm going to actually give the submission and Mr Carruthers, my colleague, may be able to add some examples and also help to respond to questions.

On behalf of the Canadian Mental Health Association, Windsor-Essex county branch, I want to thank you for the opportunity to present some of our views regarding Bill 19 for your consideration.

The Canadian Mental Health Association, Windsor-Essex branch, is an incorporated, registered, non-profit charitable organization locally established in 1971. This year we are pleased to be celebrating our 25th anniversary in providing mental health services in this community. We're one of 36 branches in Ontario, having membership with our provincial and our national associations.

CMHA Windsor-Essex has approximately 240 active volunteers who provide direct program support as well as board and committee services. The branch has a rich history in providing mental health services in this community through education, prevention, advocacy and support services. The programs and services provided are funded by government grants, United Way and supplementary fund-raising.

Bill 19, which proposes the repeal of the Advocacy Act and amendment of the Substitute Decisions Act, Consent to Treatment Act and Mental Health Act, requires the attention of every person in this province since passage of this legislation will affect the exercise of our basic rights.

Since 1976, CMHA Windsor has been operating an ombudsman program that provides a specialized function assisting individuals, families and service providers to access appropriate mental health services. We're a model program in Ontario for two reasons. The ombudsman services are provided in the three local psychiatric units and the ombudsman assists the individual through self-advocacy to access services and appeals across the municipal, federal and provincial spectrums, as well as providing support to family members and other caregivers and service providers.

Over the past 20 years, CMHA Windsor-Essex has supported the philosophy of recognizing individual rights and safeguards for vulnerable populations. As a community-based agency that has been providing services to vulnerable adults, both the psychiatric and seniors, we believe legislation for these purposes is essential.

The Windsor-Essex branch has supported the efforts of our Ontario division in its contribution to the develop-

ment of several reports. Those have been listed for you. The branch has also contributed to the hearings on Bills 74, 108, 109 and 110, the advocacy, substitute decision-making and consent to treatment legislation, in 1991.

I'm sure you need no reminder, but we'd like to let you know, as others have said before us, that we have spend hundreds of hours in consultation and involved vulnerable persons in this community and in other communities within Ontario.

In 1990, CMHA Windsor-Essex became a member of the Ontario Advocacy Coalition which has been dedicated to the establishment of an advocacy system that works for vulnerable people in Ontario. Over the past five years, our organization has been an active participant in the coalition's work in initially pressing for the establishment of an advocacy system.

The Windsor-Essex branch has supported the efforts of our Ontario office in recommending deficit reductions as a target for the government in pre-budget submissions over the past several years. We acknowledge that major changes are required in the health care system and it's essential that we create a cost-effective system which makes the best use of our resources to meet the needs of individuals coping with a mental illness and their families. To that end, the Windsor-Essex branch has been working in cooperation with the local DHC, community partners, consumers and families to plan and implement creative options to cope with the economic environment and to improve services. We can all agree, however, that the rights of vulnerable people must not be compromised by economic restraints and budget cuts.

CMHA Windsor-Essex branch has grave concerns about Bill 19, in particular the intended repeal of the Advocacy Act and other amendments to the Substitute Decisions Act, Consent to Treatment Act and Mental Health Act, and we want to highlight those now.

**Repeal of the Advocacy Act:** While acknowledging the necessity of a more cost-efficient system, it's been imperative that the needs and rights of vulnerable adults be met in a manner envisioned in the O'Sullivan report and by the Advocacy Act. We are concerned that Bill 19 may further impede the rights of the most vulnerable people in our community, the people the legislation was primarily designed to protect.

The maintenance of individual and systemic advocacy is essential. We believe that repeal of the advocacy legislation will necessitate the replacement of the present Advocacy Commission with another structure, a structure we don't know, in order to maintain individual and systemic advocacy functions as well as the functions currently performed by rights advisers acting under the Consent to Treatment Act and the Substitute Decisions Act. Our organization is concerned that the maintenance of individual and systemic advocacy continue to be upheld to protect the most vulnerable people in our community.

In the news release describing the government's intent to repeal the Advocacy Act, the statement was made that "the central role played by family members and volunteers in the lives of vulnerable people should be encouraged and supported." We've heard that spoken of today. CMHA has always supported and will continue to support



and recognize the advocacy role of various community members such as physicians, clergy, teachers, social workers and others, including the family. However, we have concerns that there be safeguards in place to protect vulnerable adults. Vulnerable adults, including seniors in cases of elder abuse, may be fearful and reluctant to report the abuse because of their real or perceived dependence upon the caregiver. It's imperative that advocates have expertise to engage these individuals so that they can determine the vulnerable adult's desires and advocate on their behalf.

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Two of the powers given to advocates under the Advocacy Act, the right of entry and the right to some confidential records, should be maintained for trained advocates as it is only through the exercise of these rights than many isolated, vulnerable persons will be able to access an advocate.

Safeguards are needed even in situations where caregivers, volunteers and family members have the best of intentions: Caregivers, who in some cases have different views regarding the best interests of the vulnerable adult, may be relied upon to replace independent, trained advocates; the Advocacy Act was predicated on a system of independent advocates, who assisted or would have assisted vulnerable persons to express their own wishes, not the wishes of the advocate.

Along with continued community advocacy, which requires the government's financial support, our organization would suggest that some form of independent advocacy body be retained to effectively provide the three functions for which the Advocacy Commission was intended: rights advice, individual advocacy and systemic advocacy. This body should remain independent of the government and be put in place as soon as possible to avoid delays to and lack of serve for vulnerable people in Ontario.

CMHA Windsor-Essex branch supports that the government fund regional offices throughout the province. As originally contemplated in the O'Sullivan report, which may I remind you was named after a Progressive Conservative member of Parliament, local individual advocacy services and rights advice could then be provided by local groups, trained by central staff. Local services could then be tailored to local needs and volunteers used to supplement services at the local level.

The Windsor-Essex county branch concurs with the Ontario division's belief that a province-wide advocacy system is necessary to protect the most vulnerable people in Ontario. While we recognize that the system created under the Advocacy Act has been controversial and costly, we believe an alternative system should be made available as soon as possible.

Amendments to the SDA: CMHA Windsor-Essex branch is concerned about any proposed amendments to the Substitute Decisions Act which will remove advocacy services provided under the Advocacy Act. It is imperative that vulnerable persons have independent advice about any proceedings which could result in a loss of rights. Under the Substitute Decisions Act, proposed amendments to section 27 could result in a person alleged to be incapable to receive notice that the public guardian

and trustee has applied for temporary guardianship of property. The vulnerable adult may not realize the consequences of this procedure, without advice, and lose the right of managing his or her property.

If there is a guardian of property appointed, our organization believes that the guardian must be accountable and provide a yearly financial statement to the incapable person whose property they manage. This has been removed through section 41, and although section 42 proposes that financial accounts are available through a court procedure, the incapable person may not be aware or able to finance this procedure.

The proposed deletion of subsections 46(10) to (12) from the SDA and amendments to section 49 would remove the present requirement for any explanation of a personal care decision to the grantor of a power of attorney for personal care, and the ability of the grantor to object to that decision. Such amendments could potentially result in an incapable person being treated against their will, although the person may be able to make an informed decision regarding the proposed treatment if it were explained to him or her in a way they could understand. Abuse of decision-making power by a substitute could also be possible under this proposed amendment, as no explanation of the proposed treatment to the grantor of the power of attorney is required, and the grantor cannot object to the proposed treatment.

As a community mental health service provider, we have advocated for the right of individuals to make personal care decisions in advance of incompetency and have those wishes honoured. The inclusion of section 50, the Ulysses clause, in the SDA addresses this need. However, the CMHA Windsor-Essex branch supports the provision of rights advice.

The ability of the grantor to revoke the power of attorney or refuse its registration has been removed from the legislation. These provisions were initially included as safeguards against unnecessary deprivation of liberty. Additionally, the new section, paragraph 50(2)4, would force the grantor to waive any right to review of a finding of incapacity. If the proposed amendments were to come into force, powers of attorney for personal care could be open to abuse, and the grantor would have no opportunity to object to the activation of the power of attorney or seek review of a finding of incapacity and could be detained against their will for up to six months if the attorney for personal care believed the grantor to be incapable of making personal care decisions and the grantor had requested an assessment within the previous six months.

The Windsor-Essex branch of CMHA has had a long-standing policy against branch staff being made guardian for personal care or property. Amendments to the Substitute Decisions Act would allow for caregivers to become court-appointed guardians if no other suitable person was available and willing to be appointed. It's our opinion that this is an inappropriate role for a service provider and can lead to conflict-of-interest issues.

CMHA Windsor-Essex branch is particularly concerned about the proposed changes to section 66, which prohibits the use of electroshock as aversive conditioning. Under the Bill 19 amendments, this provision has been deleted.



While we are aware that electroshock for purposes of aversive conditioning is presently used in very limited circumstances, we do not believe that this should be given to any person without their consent.

Amendments to section 66 would delete the requirement that the guardian not use or consent to the use of restraint or confinement unless such use was consistent with the guardianship plan. Use of restraint or confinement would still only be permitted if necessary to prevent serious bodily harm to the person or others or to allow the person greater freedom or enjoyment. Our organization believes that this proposed amendment would expose the vulnerable adult to possible abuse, as monitoring of guardians acting in home care settings would be difficult, if not impossible.

The proposed changes to section 87 would permit the use of volunteers to provide advice and assistance under this act. As an organization that utilizes over 240 volunteers in direct service and advisory capacities, we acknowledge the key role volunteers can play. It is imperative that volunteers are provided with training and support through a coordinated and regulated system.

Amendments to the Consent to Treatment Act: The proposed amendment to section 2 of the Consent to Treatment Act to include care facilities within the purview of this legislation is an important addition. We believe that such expansion of the scope of the legislation will help to prevent abuse of some of the most vulnerable people in our society—those in nursing homes, homes for the aged and rest homes—by requiring informed consent for treatments taking place in such facilities.

Although the addition of section 11 may help to prevent delays in treatment, our provincial office has expressed concern about the proposed subsection 11(b) that may be alleviated with some rewording. As written, this section may permit a person to be moved to another geographic location or another care facility to which they would not have agreed to move.

There are sections in the new Consent to Treatment Act that have eliminated rights advice. We would suggest that a provision regarding rights advice be reinserted into the legislation to ensure that a person's rights are not removed without their knowledge or understanding.

Further, amendments to the Mental Health Act: CMHA Windsor-Essex believes very strongly that responsible and timely rights advice is paramount, especially in a psychiatric facility, and should not be left to regulation, as stated in subsection 72(4) of Bill 19. It is essential that persons who not only have the knowledge but also the proper training and expertise convey the rights advice to vulnerable adults in a psychiatric facility. Rights advice in a psychiatric institution should not be provided by anyone proposing, making or administering financial, personal care or treatment decisions for the person, or anyone who receives payment for providing treatment or personal care to an involuntary patient, including an employee of a facility that would be receiving payment.

Subsections 36.2(5) and (6) of the Mental Health Act currently permit patient approval of a board-appointed representative who may access and/or consent to disclosure of a patient's medical record and patient approval of board-determined conditions on the rights of the appoint-

ed representative. The proposed amendments would permit the above activities if the patient does not object.

If this provision is changed from an active approval to a passive lack of objection, representatives who may not have the patient's best interests in mind could consent to disclosure of record, because the patient may not have been aware of or understood the right to object, and these proposed amendments could potentially harm rather than help some of the most vulnerable people in our society.

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If rights advice is removed from the Mental Health Act and left to be determined by regulation, enforcement will be extremely difficult. With no accountability, many vulnerable people may be deprived of their rights without due process.

In conclusion, Canadian Mental Health Association, Windsor-Essex county branch, along with other local agencies, community organizations, family members, volunteers and self-help organizations, have provided advocacy services long before the Advocacy Act and anticipate a continued need for the provision of our advocacy. The government can support the needs of vulnerable adults by making a provision for conflict-free, timely rights advice and advocacy, mandating the power of right to entry and access to confidential records to support the most isolated, vulnerable adults who otherwise would not have access to an advocate.

**Mr Clement:** Thank you very much for your presentation. Although you don't need me to do this, I just wanted to put on the record I'm absolutely impressed with just the brief comments you had about your ombudsman program. It appears that since 1976, you've been an integral part of advocacy in this area. You don't need me to say this, but it's very impressive, and certainly if you haven't been contacted yet, I would love, for our ministry, Citizenship, Culture and Recreation, to get hold of you to talk about your ombudsman program and see whether that is something that can be emulated in other jurisdictions.

I wanted to pass along to my colleagues as well, but I did want to talk a bit about the concept of advocacy and who will—we all agree that advocacy is necessary in our society, and the question is who delivers it and how best to structure it. I wanted your response to a quote that I'm going to take out of the O'Sullivan report, because I think it infuses some of our concerns. O'Sullivan says—it's on page 46:

"Advocacy should not be primarily adversarial in nature. Indeed, little is to be gained through an over-zealous and abrasive approach, and the costs can be high: overt or covert sanctions against residents and patients, stress, undue expenditures of time and money, increased resistance to subsequent requests and alienation of those upon whom the vulnerable person must rely."

I think those were very wise words, and I guess our concerns were that we were heading in that direction. That's our perspective. I'm not saying that's everybody's perspective, but that was our perspective.

Is there a way to balance? Governments inherently are intrusive by nature. That's just the reality of a government, of state action. By working with volunteers such as yourself and groups that are effective in the community,



is there a way that government can be supportive of advocacy without having the intrusiveness?

**Mr Vince Carruthers:** I think there is, and back in 1987—and we welcome your invitation to participate in further discussions with regard to our ombudsman program—we made a submission. We've had input in regard to this since 1987, even before that time, so we welcome the opportunity to give more information. There are other alternatives right within this book on how Father O'Sullivan had made other suggestions.

**Mr Clement:** Yes, there are a number of models that are in here that are very interesting and perhaps should be pursued; you're quite right.

**Mr Carruthers:** Yes, and that is why we're thinking that the repeal of the entire act would put us back several years. We would have to then perhaps commission another such document so we could get started again with advocacy, and I don't think that is necessary. I think just amending the Advocacy Act to perhaps follow some of the suggestions that you have would be helpful. But repealing it I think puts us back several years.

**Mr Clement:** I think that we can perhaps accomplish some goals. Sometimes you don't necessarily need legislation for government to be involved in good acts, and perhaps we need some flexibility to work with groups without the legislative framework. As I say, governments tend to be intrusive and can cause more harm than good when they get involved, even if it's for the best of purposes.

**The Chair:** Mr Klees and Mr Parker, I'm sorry. Mr Clement took all of your time.

**Mr Clement:** Sorry.

**The Chair:** Mr Duncan, please.

**Mr Ramsay:** I can't believe it.

**Mr Duncan:** You had indicated that as part of the O'Sullivan report, you had been consulted about it and were asked to participate. Is that correct?

**Ms Hayward:** Yes.

**Mr Duncan:** And before the introductions of Bills 108, 109 and 110, you were consulted and involved in the development of that legislation by the previous government?

**Ms Hayward:** That's correct.

**Mr Duncan:** Have you been consulted at all prior to this legislation—by the government?

**Mr Carruthers:** Yes, we have. Through the Minister of Citizenship's office, we have been identified as a resource for some future advocacy programs. However, again we're being consulted in regard to what we could do differently.

**Mr Garry J. Guzzo (Ottawa-Rideau):** The answer to the question, though, is yes.

**Mr Carruthers:** Yes.

**Mr Guzzo:** Tell Mrs Caplan.

**Mr Duncan:** So you were consulted about Bill 19 before it was introduced?

**Mr Carruthers:** We weren't consulted in regard to Bill 19, we—

**Mr Duncan:** Oh, you weren't consulted with regard to Bill 19.

**Ms Hayward:** Not in regard to the bill. We were consulted as to getting more information on the type of services we provide.

**Mr Duncan:** I had one question I wanted to ask you about the psychiatric patient advocacy office and whether you have familiarity with it. One of the ideas that we've conceived is in terms of providing some expanded mandate for the PPAO to not only serve a facility but to serve a variety of programs and in effect take up some of the advocacy functions. Have you any thoughts about that? Do you think that might be one basis of an expanded advocacy service?

**Ms Hayward:** Certainly, one of our main concerns is conflict of interest. There needs to be a system put into place so that organizations such as ourselves are not presented with a conflict. There may be some potentials for that office to provide advocacy within other jurisdictions besides where a psychiatric hospital is, certainly.

**Mrs Boyd:** Mr Clement suggests there's no reason to have legislation to cover this, but you've been very clear in your submission that the issue about right to entry, the issue about the access to records, may be necessary in order to advocate properly, and certainly we've heard that again and again.

The other issue that you raise is that consistently you talk about rights advice needing to be built in. I assume you mean the legislative protection people have when we legislate that they are entitled to rights advice and that that's what you are talking about and that's what you're concerned about even in the Mental Health Act, that that rights advice is going to be regulated rather than legislated and that's one of your major objections to this, that this protection is not there in law, so it can't be challenged in law.

**Ms Hayward:** That certainly is a concern that we hope we have identified in our presentation. Rights advice is paramount, and unless it is legislated and there is a legislated role for someone to be able to gain access, there will continue to be vulnerable persons who—and organizations such as ourselves, even though we work with many volunteers and have staff members who can provide support, cannot get access unless there is something legislated.

**The Chair:** Mr Marchese.

**Mr Klees:** Mr Chairman, I have a point of clarification.

**Mr Marchese:** Could you do that after?

Just some quick points that I wanted to agree with you on. Many, many, many deputations have said much the same, worded differently perhaps, but the concerns don't seem to be very different. In the end, if the government disregards some of the suggestions many of you have made, I will be completely shocked, because there are consistencies in people's concerns.

Areas around confidentiality have been talked about by many groups. Your concern about "Rights advice in psychiatric institutions should not be provided by anyone proposing, making or administering financial, personal care or treatment..." has been mentioned consistently by virtually every group that's come before us. The whole point about having service providers being made guardians has been mentioned as a concern by many, even though the government members think, "Well, if the court decides it's okay, then it's okay." Many people still believe that it's not, that it's a problem, it's a conflict.

And you made a whole host of other suggestions that other people have also consistently agreed with your submission as well.

The point of right to entry: That's what groups have been saying. If they have no authority to deal with areas of abuse, then we've got a problem. The flexibility the members talk about: I don't understand what it means. The training of volunteers: I don't understand what that means. What people need, what people have told us over the years that they needed, was an advocacy act, with advocates and rights advisers. For years they have told us that this is what they wanted.

If they were unhappy with that act as it was, they could have reduced it. They already cut \$7 billion or \$8 billion out of that commission anyway. They could have cut further, I suppose, and they would have, but they could have left some skeleton out of that program that would have at least made people happy that they would have had something.

They're taking all of that away. There will be no advocacy left. They say that there will be advocacy. I'm not sure what they're talking about. The government is getting out of the field of advocacy, because, Mr Clement says, "The government is too intrusive by its very nature, so we shouldn't provide advocacy as a government; it's wrong," I presume they're saying.

It offends me. It really, truly offends me that government will do nothing for advocacy or rights advisers. They have an obligation to tell us what they mean by advocacy, and they haven't told us. They have an obligation to tell us what they're going to practically suggest, and they have not told us. It would have been nice.

I'm sure that you would agree with that.

**The Chair:** Thank you very much, Mr Marchese, Mr Carruthers and Ms Hayward. We appreciate your presentation.

**Mr Clement:** He has one point of clarification to make.

**The Chair:** A point of clarification on a Friday afternoon. How can I help you?

**Mrs Boyd:** It's only Thursday.

**The Chair:** It feels like Friday.

**Mrs Boyd:** It feels like it, doesn't it?

**Interjection:** Boy, does it feel like Friday.

**Mr Klees:** Is it Friday in Windsor?

**Ms Hayward:** We have our own calendar.

**Mr Klees:** A point of clarification, if I might, and I think this would help you: I think your concern with regard to having regulations—this was your last point—that it wouldn't be enforceable, I just want to point out to you that under the Mental Health Act there is a provision for offence issues incorporated into that legislation, so non-compliance with regulations would actually result in

an offence under that act. So there is enforcement of a regulation in place there and I think it would probably solve the—

**The Chair:** Thank you, Mr Klees.

**Mr Parker:** Mr Chairman, if we're into clarifications, I have just three brief points to make.

**The Chair:** Around this table, no one is terribly brief. You have one minute.

**Mr Parker:** If I could refer you to page 4 of your submission, I just wanted to give you some comfort on three points that you make on page 4 of your submission.

You comment that there is a lack of financial accountability under the new regime. The existing law required annual reports to be given. That has been removed.

There is a still a regulation-making authority under subsection 60(2) of the bill that's proposed. I'll just refer you to that section, and that section addresses the point you have raised.

You expressed the concern that decisions can be made without the knowledge and against the interests and wishes of the incapable person if a substitute decision-maker has been appointed. I just want to refer you in that context to section 66 and section 68 of the Substitute Decisions Act. Those sections safeguard those points, and those sections are not amended under the bill. So those sections survive Bill 19. They are to be found in the Substitute Decisions Act.

**The Chair:** Thank you, Mr Parker.

**Mr Parker:** And the right to revoke the Ulysses contract—

**The Chair:** No, Mr Parker, I'm sorry. I've got to ask the other side now if they have any points of clarification.

**Mr Carruthers:** I was just wondering if perhaps the government could identify, perhaps, why there haven't been any provincial offence charges in relation to the Mental Health Act since 1986, when that was put into place. I would suggest that it is because the people are still very vulnerable in the institutions and they need advocacy in order to assist in even laying a provincial offence.

**The Chair:** Okay.

*Interjections.*

**The Chair:** To be fair, are there any points of clarification?

**Mrs Boyd:** I think the presenters are well aware that an ephemeral regulatory authority, without the regulations, is little comfort.

**The Chair:** I thank all members of the committee for their cooperation in this long and trying week. We are adjourning to 9:30 am on Monday, February 19, 1996, in committee room 1 at Queen's Park.

*The committee adjourned at 1455.*



## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

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Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Oriole L) for Mr Conway

Clement, Tony (Brampton South / -Sud PC) for Mr Tilson

Duncan, Dwight (Windsor-Walkerville L) for Mr Chiarelli

Johns, Helen (Huron PC) for Mr Hudak

Marchese, Rosario (Fort York ND) for Mr Hampton

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** McNaught, Andrew, research officer, Legislative Research Service

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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Monday 19 February 1996

# Journal des débats (Hansard)

Lundi 19 février 1996

**Standing committee on  
administration of justice**

**Comité permanent de  
l'administration de la justice**

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Monday 19 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Lundi 19 février 1996

*The committee met at 0935 in committee room 1.*ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

**The Chair (Mr Gerry Martiniuk):** Good morning, members and ladies and gentlemen. This is the continuation of the hearings of the standing committee on administration of justice in consideration of Bill 19, the Advocacy, Consent and Substitute Decisions Statute Law Amendment Act. I welcome to the committee today Mr Morley Kells, member for Etobicoke-Lakeshore, and Mr Mike Brown, member for Algoma-Manitoulin.

## ALAN SILVERSTEIN

**The Chair:** Today, Mr Silverstein is on first and he has one half-hour. We shall proceed. Mr Silverstein, it's all yours.

**Mr Alan Silverstein:** Thank you, Mr Chairman. I've prepared a memorandum. I'm assuming the committee members have a copy of it.

Very briefly, my background: I am a lawyer in Toronto. I have been practising since 1977 in real estate and other related fields. I've seen powers of attorney—and that's really my focus this morning—for property go through a number of different phases, from the time when a power of attorney became invalid if the donor became incapacitated to the pre-SDA regime, to the SDA, to possibly Bill 19. So I speak from the experience of clients and the other exposure that I've had to powers of attorney, having written many times about it in the Toronto Star in my weekly column and talked about it on CFRB radio.

A lot of criticism was levelled about powers of attorney because of the fact that, the way the SDA was worded, the public guardian and trustee had the ability to take charge of a person's affairs if they did not have a power of attorney and became incapacitated. I was

disturbed by another provision of the SDA which allowed the public guardian and trustee to become statutory guardian of property even if a continuing power of attorney existed. People said, "How is that possible?" You have to really wade through the legislation to realize that the enabling sections, which enabled you to exclude the public guardian and trustee, or the public trustee as it then was, were repealed by the Consent and Capacity Statute Law Amendment Act, which was passed at the same time as the SDA in 1992. Therefore, you had the situation that even if a person had a power of attorney, there was a discretion in the hands of the public guardian and trustee to override a power of attorney.

I had a lot of discussions with people and I said, "If you look at the very first form, it talks about reclaiming the power from the public guardian and trustee if you are a named attorney." So that was my concern, as much as other people were concerned about the fact that the public guardian and trustee could step in when there was no power of attorney.

In my memorandum, I've really laid it out in three different areas: the background, the changes and areas that I think require further work.

Let me go through the background very quickly. No longer could a continuing power of attorney stop the government from being involved in our affairs; I've mentioned that. The province, through the public guardian and trustee's office, could override a power of attorney; again, that was my concern. To go through how that was possible, section 16 talked about the assessment process. It contained what I call a perverse reverse presumption: Unless someone specifically said no at that stage—and if they were in a coma, it became impossible to do so—then the public guardian and trustee had the power to assume control of property even though there was a valid continuing power of attorney and effectively terminate its existence. A lot of people, when told about this override, expressed concerns about it.

Subsection 17(1) of the current SDA says, "The attorney under an incapable person's continuing power of attorney may apply to the public guardian and trustee to replace him or her as the person's statutory guardian of property." Well, why would you ever have to apply to the public guardian and trustee to take back a power if you had it in the first place? Here we were, thousands of people signing government kits, signing powers of attorney, and yet the government itself had the power to override that very power of attorney. It didn't make any sense.

Nowhere did the SDA say the public guardian and trustee would be a substitute decision-maker. We kept hearing it time and time again: It was policy, it was policy, it was policy. But the words didn't appear any-

where in the SDA. An admirable policy, but one that was not in writing.

I viewed the SDA, at least this part of it, as an unwarranted interference in people's affairs because of the very broad and undefined discretion being given to the public guardian and trustee to override a power of attorney. It effectively allowed state management of affairs and assets in these circumstances. How does Bill 19 improve this? I'll be very frank: I feel Bill 19 goes a long, long way, not only to improving the system but to reflecting the wishes of the people of Ontario. I have hundreds of letters that I received in response to my Toronto Star articles supporting my position.

0940

First of all, the assessment process has been totally revamped. The new section 16 says someone must request the assessor to perform an assessment; an assessor just cannot go out on his or her own. The person requesting the assessment must first of all have reason to believe a person's incapacitated. Secondly, they must make inquiries if a continuing power of attorney exists covering all of a person's assets. There was no requirement like this under the old section 16. Thirdly, they must make inquiry and be satisfied that no family member plans to apply to become a court-appointed guardian. So the section lays out the three alternatives very clearly. You have to inquire if there's a power of attorney, you have to inquire if they want to go to court, and only if those two situations are not going to happen, will the public guardian and trustee get involved. So the three alternatives are laid out clearly.

Furthermore, the role of the public guardian and trustee is clearly stated. We have subsection 24(2.2) which says that the public guardian and trustee will only become a court-appointed guardian of property "if no other suitable person...is available and willing to be appointed." We now have in writing—or we will have if this legislation is passed—that clear statement that the public guardian and trustee will only be involved if there's no one else available. What about the situation, though, that I talked about earlier, the override? That's also going to be dealt with, as I'll show you in just a moment.

The legislation cleans up some of the requirements about security. These are more technical issues.

What the legislation does, in my opinion, more than anything is recognize the predominance of a continuing power of attorney for property. I want to repeat that, because it's so important: It recognizes the predominance of a continuing power of attorney for property. Bill 19 makes it very easy for a named attorney in a continuing power of attorney to retrieve the powers from the public guardian and trustee if the public guardian and trustee somehow becomes involved through inadvertence or otherwise, if the CPA covers all the person's property, as most of them do.

How is this new system so simple? If it turns out that a family member goes to the public guardian and trustee and says, "We'd like you to become statutory guardian of property," and afterwards it appears there is a continuing power of attorney—perhaps it was locked in a safety deposit box—all the attorney has to do is sign an undertaking to honour the provisions of the CPA and the

public guardian and trustee will back off. This recognizes the predominance of the person's wishes. You sign a CPA; that's what you want to have done. Somehow the public guardian and trustee becomes involved, the valid CPA surfaces, the public guardian and trustee will back off, will relinquish his or her powers based on this written undertaking.

Any lawyer involved with the term "undertaking" knows that it's a very simple document to draw up. As a matter of fact, I asked officials down at the public guardian and trustee's office, "Will there be a prescribed form?" and I was told no, it's such a simple form they don't even have to prescribe it in regulations.

This eliminates the override that I was talking about earlier and that so many people expressed concern to me about, because now, if the public guardian and trustee gets involved, they will relinquish the powers, if the CPA covers all of the person's property, once the attorney produces the CPA and signs the written undertaking.

There is an important section which a lot of people are not aware of in Bill 19—section 77. It's really important to emphasize to the public that valid continuing powers of attorney will continue to be valid after Bill 19 is passed, assuming it is passed. So many people have called me and so many people have written to me, "Will my power of attorney be valid?" There's real need to emphasize that anything that was valid before will remain valid in the future.

Another change made by Bill 19 is to make the same standard for witnessing for wills and for powers of attorney. Under the SDA, we had two different standards—a much more stringent standard for powers of attorney than for wills. Yet from my experience when people sign wills they sign powers of attorney, and when they sign powers of attorney they sign wills. One minute you've got one standard and one minute you've got a second standard. What the legislation has done is recognize there is one standard for both types of documents.

What remains incomplete? I go through a few technical points in my memorandum. For example, there's reference once to the person as opposed to the document. I'm concerned about what happens if the person requesting the assessment can't satisfy things. It should clearly say a certificate of incapacity will not be issued. There should be a priority ranking for who can apply to the public guardian and trustee if there is no CPA. What happens if there's more than one suitable applicant? Is there any penalty for putting the public guardian and trustee through the wringer and then having to reclaim the power afterwards, or the attorney reclaiming the power? In other words, what happens if it's an unnecessary process?

But the real concern I have is the absence of an affidavit of execution. We've seen in the last 10 years the real estate industry, with the registration of documents, move away from affidavits—and it is a system that is open to fraud, forgery and abuse. There is absolutely no reason why we should have different standards for wills and for powers of attorney, and yet the legislation perpetuates this. What we have for a will is an affidavit of execution being essential before it can be probated. On the other hand, we have powers of attorney being signed without any affidavit from the witness. I think it is



absolutely essential to ensure that the person did sign the power of attorney, that you have the witness swear an affidavit as well. There will be criticism, of course, saying, "People can't do their own powers of attorney, they can't rely upon the kits." You can grandfather anything that was done before.

But on the other hand, to ensure that people are signing documents that are very, very important and very effective and very powerful, there should be an affidavit of execution attached to a power of attorney before it becomes valid to, again, correlate wills with powers of attorney.

Lastly, there should be a process so that if people want to challenge the validity of a CPA, the SDA should provide for this. There is provision in the Succession Law Reform Act that deals with challenging wills based on lack of mental capacity, presence of undue influence, non-compliance with formal execution requirements and the like. Those sections could be easily lifted into the SDA through Bill 19 so we've got the same system.

As I said, a lot of people sign wills and powers of attorney at the same time; the same standards should apply to both. We're certainly moving in that direction, but on the other hand, there are still areas that do require some improvement before Bill 19 becomes law.

That is my presentation. I'm certainly open to any questions from any committee members.

**Mr David Ramsay (Timiskaming):** Thank you very much for your presentation this morning. On your last point, that you feel it's necessary that there be an affidavit of execution, what would be the downsides of that, if we brought that in? Would this delay—

**Mr Silverstein:** Delay what? The legislation?

**Mr Ramsay:** No, no, delay the process.

**Mr Silverstein:** It would probably ensure that people are signing the documents in the presence of either lawyers or notaries, and that's the only downside. The witness would have to get the affidavit sworn. But again, if you emphasized that anything done to date is valid, therefore anybody who used the kits to date would be able to rely upon them. You could have a cutoff date; any document signed before that date doesn't require a witness, any document signed after that date does. The date would be one of the things you'd have to check to see whether or not there was an affidavit attached.

**Mr Ramsay:** Would there be a charge attached to this?

**Mr Silverstein:** Depends on who is doing the commissioning of the affidavit. Certainly lawyers don't charge when they're doing it for clients. A lot of lawyers will charge a nominal charge for an affidavit of that nature. But again, it protects the public in the sense you have the witness now swearing he or she did see that act take place. It's protection for the public, protection for society at large.

**Mrs Elinor Caplan (Oriole):** The existing kit does not require witnessing by a lawyer or a notary.

**Mr Silverstein:** That is correct. I'm not saying the witness has to be a lawyer. I'm saying the witness has to swear an affidavit.

**Mrs Caplan:** But that's not the case now.

**Mr Silverstein:** No, it's the same thing. Anybody can be a witness today, anybody can be a witness later, but

the witness will have to go to a lawyer or a notary to swear an affidavit that he or she did see the donor of the power sign the power. To be frank, and I know this is not the right committee, I would like to see affidavits come back into real estate. That's another committee's meeting, I know. But it eliminates the situation where you might have fraud, abuse, undue influence, because at least someone will have to swear an affidavit, and if they feel reluctant to do so, they won't swear it.

**Mrs Caplan:** The concern that I have with it is the one that my colleague raised, and that is that it does add an expense. Most people don't realize that their MPPs can act as notaries and do that without a charge to them.

**Mr Silverstein:** Then it's the job of the government to make sure that point is emphasized. On the other hand, if a power of attorney is being challenged for being invalid, for abuse or misuse or forgery or fraud, the cost involved there is much higher than perhaps \$10 or \$15 to go to a notary. I'm sure groups will be out there, and maybe you would appoint notaries in seniors' organizations so that they can notarize them at no charge. That's a possibility too.

The government controls who the notaries are. Perhaps they could have a process to set up a notary system so that they notarize these. You can have limited commissions. A commissioner can have very limited powers under the commissioner of oaths act, and that's all you need. Therefore, you could have a commissioner appointed to do that very purpose. There are ways of overcoming this, but the protection is much greater than the system we have today.

0950

**Mrs Caplan:** You also make a good point that nowhere in the legislation, the SDA, does it say the public guardian and trustee would be a substitute of last resort. That's a very important point. My own view is that everyone wants the public guardian and trustee to be the last resort, and one of the concerns that has been raised at committee is that in the hierarchy, by lumping parent and children together, if they disagree, the public guardian and trustee would be called in to resolve the dispute.

**Mr Silverstein:** There are two things you just raised there; number one, what you've just mentioned as the first point, but, secondly, perhaps the hierarchy should be split up. I mentioned that here. Perhaps we should have a ranking system. The Consent to Treatment Act does provide for a ranking system. I could not understand why there wasn't a ranking system when it came to this part of the SDA. It just didn't make any sense. The same laws were being passed, and yet one had a ranking system, one did not.

**Mrs Caplan:** I think that is a very good point, and I hope the government will listen and respond to that, because I think not only should the SDA have a hierarchy but that even within the consent to treatment, I think the hierarchy should be split so that parent and children are not in them, primarily so that you will ensure that the public guardian and trustee, as best you can, is the last resort. Are you proposing a specific clause be added, and, if so, where would you put that clause?



**Mr Silverstein:** You have the hierarchy labelled, but not as such in the SDA, where it talks about who can apply to the public guardian and trustee. You can say, as I believe the Consent to Treatment Act says, that this is the hierarchy, in other words, priority. Number one has priority over number two, and two priority over number three.

I want to emphasize again, dealing with your first point for the moment, not only does it say so clearly, dealing with the public guardian and trustee and the courts, but the ability for the attorney to effectively reclaim the power states again that the public guardian and trustee will relinquish the power. So you have all three situations covered. In other words, if you're explaining to the people what are the three options, it's very clear: Number one, sign a power of attorney; number two, have the courts get involved; number three, have the public guardian and trustee get involved. Take your pick. There are only those three choices.

**Mrs Caplan:** There is one other point here that numerous presenters have mentioned, and that is that the new health care consent legislation does not require notification of rights and information about right to appeal. You didn't mention that in your brief.

**Mr Silverstein:** No. My experience is strictly that dealing with continuing powers of attorney for property. That's the type of practice I conduct. Those are the concerns that have been expressed to me. I'm not as cognizant of those concerns, and therefore I unfortunately do have to pass comment on them.

**Mrs Caplan:** That's fine. On the issue, you're saying that your experience is with power of attorney for property.

**Mr Silverstein:** That's right.

**Mrs Caplan:** Have you had any experience with power of attorney for personal care?

**Mr Silverstein:** We've signed them at the same time but we've never had to use one yet. I'm fearing the day when we do because I know it's a very tragic situation. But, again, most people when they come in—now when people come in to sign wills, it's usually definition of wills; power of attorney, property; power of attorney, personal care.

**Mrs Caplan:** Thank you.

**Mrs Marion Boyd (London Centre):** Thank you very much for your presentation. Your point 5, that the status of continuing powers of attorney needs to be clarified, is right. We've heard from a number of people that they clearly don't understand that those would continue to be in place, so I hope that will be taken care of in the amendments.

I am very interested in your points on pages 5 and 6, what you call the unfinished parts, because I think you're quite right. There isn't a very good clarity about what you do when there is more than one potential applicant in terms of this. Have you any suggestions as to how that could be done? Do you think this hierarchy would resolve that?

**Mr Silverstein:** I think the hierarchy is part of it.

**Mrs Boyd:** Yes.

**Mr Silverstein:** One of my secretaries got married in the fall and she had been in a tragic accident and there

was need to get the public guardian and trustee involved. Is it her parents of 24 years or her husband of two months who would be able to go to the public guardian and trustee? That's the kind of situation we're trying to deal with, where both would say, "We should be appointed," and the legislation should make it clear what the hierarchy is, unless of course, just like a will, you write your own rules. That's the whole idea.

**Mrs Boyd:** The hierarchy in that case would say a spouse, wouldn't it?

**Mr Silverstein:** That's right. But again, just like wills, if you don't have a will, the laws of intestacy say what your will is. If you don't have power of attorney for property, the law of the province will say what the hierarchy is. If you don't like it, make your own. If you don't do your own, these are the rules.

**Mrs Boyd:** So you think it should follow, for example, the same order as the intestacy one, and that would then separate parents and children?

**Mr Silverstein:** That's correct.

**Mrs Boyd:** Because this has been mentioned as a real issue, and I think it is.

**Mr Silverstein:** Absolutely. Again, there has to be a closer drawing of the wills legislation and the power-of-attorney legislation. I think if that's done, you'll probably see the public understand the whole process much better.

**Mrs Boyd:** I know that property is more your area, but one of the concerns that's been raised is the possibility that someone who is a child of a person could witness their continuing power of attorney, and that this might be a conflict of interest. That's true for both personal care and for property. Can you comment on that? Do you see that as a possible conflict?

**Mr Silverstein:** That's also a possibility with wills, and there's always the provision that the matter could be resolved by a judge in court. In other words, whenever there is a potential conflict, the judiciary has the power to say, "We will waive that conflict in these circumstances—not in every circumstance, but here."

**Mrs Boyd:** But I thought children who were going to benefit under a will, anyone who benefits under a will, could not be a witness.

**Mr Silverstein:** But there is an override provision that the courts do have, and again maybe that's what we need here. We're not trying to make this one section 30 pages long. On the other hand, if there are safeguards in the wills legislation, perhaps they should be here as well.

**Mrs Boyd:** I think you make the point very well that the whole purpose of this exercise is to make what we've got work better, and certainly some of the complications that you talk about clearly were unnecessary and need to be resolved. I think a lot of the concerns that you've raised about those are real.

On page 6 under number 5, you talk about what happens to the person who wilfully requests an unnecessary assessment, what happens, for example, where someone asks for an assessment that isn't necessary. What would you suggest as an appropriate penalty?

**Mr Silverstein:** I'm not sure myself, but I'm concerned about the person who says, "Well, they'll never find the power of attorney"; they're going to have a tough time finding it, but they know it exists. That's one



thing I was racking over in my head, and that's why I didn't come up with a proposal, because I'm really not sure what the penalty should be.

**Mrs Boyd:** It's really fraudulent, isn't it, if you know one exists?

**Mr Silverstein:** That's right. On the other hand, somebody may say, "I'd like to be able to get involved unless they can find it." It's food for thought more than anything at this point.

**Mr John L. Parker (York East):** Thank you very much for your very helpful comments this morning, and thank you for your support for this legislation. We're hoping it solves a lot of the problems with the existing legislation, and we're encouraged to get support from people who are knowledgeable in the field.

I found your remarks very clear, but I think perhaps in the questioning some confusion may have arisen, so I want to address some of those points off the top if I might; first, concerning point 5 on page 5 of your paper. Here you refer to section 77 of the bill, and it was suggested in questioning that it is hoped this matter will be taken care of in the amendments to come. You're not suggesting any amendment here, are you? You like section 77 as you read it.

**Mr Silverstein:** I like section 77, yes.

**Mr Parker:** Your recommendation to us is that we give proper profile to it so that it is recognized out there that section 77 is in there.

**Mr Silverstein:** May I use your word "profile" when I do it in my newspaper article next time? Thank you.

**Mr Parker:** If you would. So you're not asking for an amendment there; you like what you see.

**Mr Silverstein:** No; I do, yes.

**Mr Parker:** On the matter of beneficiaries under a will, the rule is that if you are a beneficiary under a will, you may not be a witness to that will. That's the standard rule; that's standard common law.

A power of attorney doesn't do the same things as a will does, does it? A will disposes of property to certain beneficiaries. Somebody stands to gain from receiving something under a will, and if you're going to get something under a will, it's hardly appropriate that you be a witness to that will. But in a power of attorney, it's not a matter of disposing of property; it's a matter of allocating the authority to deal with someone's property or with somebody's decision-making capacity. One doesn't benefit from that. One takes on a responsibility to be exercised in favour of the grantor, which is entirely different in this case than a will, isn't it? The grantor hardly benefits from a will.

**Mr Silverstein:** No, but it's a question of entrusting the power, and that's the point. When you sit down with people, they say, "I am entrusting someone with the power to be in charge of my affairs if I become incapacitated." In many respects they look upon it the same way. In other words, who's in charge? That's why the independence is so important, and if you want to put an override in the event of inadvertence, that's fine too. But the point is, it should be made clear at the outset that you should not be a witness if you are the grantee of the power.

**Mr Parker:** That's provided for, that the grantee, the one who is given the power, cannot be a witness, but

that's not to say that a child of the grantor is necessarily going to benefit from the document.

**Mr Silverstein:** There's always the possibility of abuse, and that's the concern people have.

**Mr Parker:** And as you pointed out, the courts are there to protect us against that sort of thing.

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**Mr Silverstein:** Yes, there's no question.

**Mr Parker:** So I take from your comments that you don't see any need for an amendment to the proposed legislation in this respect, do you?

**Mr Silverstein:** It's something that could be considered. I would prefer that it not be there, to be frank with you, because I'd like to keep it clean. If you're a witness, you can't be the donee of the power, the grantee of the power.

**Mr Parker:** But the concern that was raised in questioning was whether a child of the grantor could be a witness.

**Mr Silverstein:** There could be situations where there are not a lot of people around. You need two witnesses; you have one witness who's independent and there's another person, somebody's quite ill and that's the only other person around, maybe an only child, it may be in a hospital room, it could be in northern Ontario, it could be anywhere where people are not around and there are only two people available. One witness invalidates it, clearly; two witnesses, one of whom is the donee, would also invalidate.

**Mr Parker:** Frankly, we see it the same way and that's what the proposed legislation reflects. I think we're in agreement on that point.

**Mr Silverstein:** Exactly.

**The Vice-Chair (Mr Ron Johnson):** I'm sorry, I'm going to have to cut you off here. Your time has expired.

**Mr Silverstein:** I want to thank you on behalf of the committee for your presentation.

**Mrs Helen Johns (Huron):** A point of clarification, Mr Chair, while these people are coming up: In his unfinished section, highlight number 3, is there a priority ranking? I just want to draw to the attention of the people around the committee table that subsection 18(3) in the Health Care Consent Act may well provide that. I didn't get a chance to ask him on what he really wanted there, but subsection 18(3) is the ranking that would take into account the priority ranking he's asking for, in (c), unfinished business, page 5 of his report.

**Mrs Caplan:** Point of order, Mr Chair—

**The Vice-Chair:** I'm sorry, Ms Caplan, the presentation is ready to start here.

#### HALDIMAND-NORFOLK WORK GROUP OF SIMCOE

**The Vice-Chair:** Next on the list will be Mary Taylor, Haldimand-Norfolk Work Group of Simcoe.

**Ms Mary Taylor:** Good morning, everyone. I'm very, very happy to be here this morning to bring you some information that I think is important. Particularly, it pertains to economic development and how it will act as an advocate for our vulnerable populations. I would like to begin my presentation this morning by showing you a



short eight-minute video of one of the entrepreneurial small businesses that is attempting to help vulnerable populations.

*Video presentation.*

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**Ms Taylor:** I would just like to say that those of us who have been involved over a number of years with psychiatric survivors and people who are living on disability pensions and on public assistance know that one of the most positive forms of advocacy is economic development. We have examined this from every point of view. We have looked at it from people going back into hospital, from people being healthier in the community, from people being able to earn, and particularly from people having a chance to learn new skills, to have a trade.

I bring to you this morning the idea that we are, I believe, all looking for solutions, solutions to problems that have become very deeply ingrained in our society. One of those enormous problems is poverty, the growing poverty of our vulnerable populations, of people who are on limited incomes, of people who cannot seem to get beyond the poverty line.

One of the things I really would like to say to you this morning is that in Third World countries they have come to rely on economic development to alleviate the suffering and the poverty that is there—through the United Nations, through building community economic projects. I think here in Canada we have a fourth world. When we talk within our community of common bond, we often refer to ourselves as belonging to the fourth world. We define the fourth world as a developed country, but where there are a number of people who become disfranchised for a number of reasons within that community.

It is made up of people with many disabilities, psychiatric disabilities, developmental disabilities, ethnoracial and cultural groups with disabilities, aboriginal people with disabilities, and our young people, many of our young people who are getting out of high school today and have not been able to finish, where their option is not to go on to college or to university, where there are no jobs for them, where they have lifetimes of poverty ahead and unemployment.

How do we solve this problem? How do we begin to look at this problem? It will not be resolved through indifference. It will not be resolved by trying to give inch-by-inch increases to small disability pensions or to welfare. It will be resolved if all of us come together and we look at ways, at strategies that will help people to learn in a different way, where there is some application to how they learn and what they need to learn. It will come through commerce and through marketing and through people having a chance to give of their talents, to earn and to contribute to the common good. It will come through people being industrious and living with perseverance and living with hope and opportunity.

I believe, with the rescinding of the advocacy bill, if there is any way that we can put something in its place, I think very serious consideration should be given to building small businesses and a commercial enterprise. What else is there that we can do?

Each year our economy is moving away from an industrial base to a technological base. The more technologically based we become, thousands and thousands of jobs are being lost, and these jobs are not jobs that will be reinstated. They are lost forever. So what we have is a widening gap, a polarization between the haves and the have-nots. In five years, if we continue this trend, we will have developed effectively a level of poverty within our borders that we will never extricate ourselves from.

The time is now where we need to look to utilize people's talents, to utilize their industry, to come together and to build a marketing system that is throughout Ontario. Some of this groundwork has been laid. We have done some of the work. We have not been lazy over the past 10 years, nor have we not realized the plight that we're in.

In 1981, Abel Enterprises began as a small economic project for psychiatric survivors. We have moved along. We have found the benefits when people can work, in lessened hospitalization, in people not having to live in the worst places in town. A small income, even if your allowable income is only \$160 a month, is the difference between having a pair of shoes and not having a pair of shoes, between living in a run-down boarding house and perhaps having something a little better. It brings hope. What it also brings is a challenge to the human spirit, and what it also brings is a society and a community saying to people: "You belong with us. You should not be separate and polarized. You belong with us."

The contribution that people can make with their talents is enormous. The wonderful products that are made within our establishment are only a very small possibility of what could become part of the greater good.

What I tried to bring to you this morning is not a lot of grumbling and bemoaning and saying how awful it is and what is happening. What I'm trying to bring to you is a way to resolve.

On behalf of people who have the talents to do what they need to do, before I close I want to bring one important message to you and it is this: It is that many people have the misconception that they can give a little seed money to economic projects and within a few years they will all become self-sufficient and then everybody can walk away. That is not the truth. That is not the way it can be.

As long as the system functions the way the system functions, there will be a constant need for support. Where the great benefits are is that other small businesses and communities are supported by buying products and goods there, and the less of going back into hospital, and also the fact that many people who would go on to pensions, do not go on to pensions because they're able to sustain themselves.

Just one last point, and that is that the more commerce we have, the more we grow, the stronger country we become. It belongs to all of us, and God bless this country. Thank you. I'm open for questions.

1020

**Mr Rosario Marchese (Fort York):** Thank you, Mrs Taylor for your presentation. A number of people have spoken to some of the issues you've spoken to, perhaps in different ways, but the concern is very similar.



When you repeal the Advocacy Act and you eliminate the commission, including rights advisers, you're eliminating an important part of what I think you're talking about, because what people have been saying is that the commission, the Advocacy Act, its advocates, are a focal point of being a part of as opposed to being disfranchised. If you eliminate that, you really are putting us out again, and what it allows people to do, through this commission, through the Advocacy Act, is to be able to have a voice. If you take it away and you put nothing in its place, you're effectively taking people's voices, as it relates to issues of the very kind that you spoke about and that we've seen today.

I think many people have spoken to this. I would be very concerned that the government wouldn't listen to this component of it, and what you've said is that at the very least, the government has to put something in its place.

Do you have a sense of what that thing could be?

**Ms Taylor:** Yes. What I would like it to be, if we could do a magical thinking thing here and say what it would be, it would be a corporation with some funds that would support small businesses being set up throughout the province, and perhaps ideally the core model in each community would then develop small satellites where people could go through the program, like an apprenticeship, and then move on to have their own entrepreneurial businesses and at the same time the corporation would be responsible for building a collective marketing system.

With *Prezance Of Mind*, it is one store that is very tiny, but it is geared to selling the goods of people who are poor. You cannot put stuff in there if you are wealthy. It is for poor people. We are opening another one in Waterford in Ontario which is *Prezance Of Mind* number two. We have plans to open a small one in Kitchener. If this marketing system could be throughout Ontario where we could market back and forth, we could develop a wonderful commercial entity that would serve the poor, and it would serve all those tiny communities, the hardware stores that are trying to sell their goods, whatever kind of store. It increases the economy. So this is what we would like to see.

I do have a model down in black and white, if anybody would like to see it at some time in the future.

**Mr Parker:** Thank you very much for your presentation this morning and thank you for the very significant video that you showed us. We're into our third week of hearings on this bill starting today, and we've received deputations from many people who have clearly suffered greatly in life, and they continue to suffer with one limitation or another that has weighed them down: no fault of their own; it's a condition they've been born into or has attached itself to them over life.

Many of these people have pleaded with us to retain the Advocacy Act, as though it's some sort of lifeline that will save them from the condition they're labouring under. I go back and I read the Advocacy Act and, frankly, I just don't see anything in it that's going to solve the problem they've got or address the concerns they have or improve their condition in the way they would wish it to be improved.

Frankly, I see your video this morning, and I'm inspired. What I see there is a group that is doing something, that is giving the kind of hope and giving the kind of self-worth and dignity to the people who we have been hearing from for the past two weeks, and giving them a chance to get on their own two feet and feel some value for themselves, and to show that they matter and to show that they mean something.

In a world of limited resources, and as a government, we have to make choices as to how we allocate those resources. If we have money to spend, if we have public resources to allocate to people with those needs, would you rather see it put towards the type of model that is represented by the Advocacy Act and the Advocacy Commission or the kind of work your organization is doing, the kind of thing we saw on your video this morning?

**Ms Taylor:** I think I can best answer your question by saying this: I don't think it should be an either/or question. I don't think it can be an either/or question. I think people who are vulnerable become vulnerable economically. If you're vulnerable economically, it affects your whole life. You can also become vulnerable because you don't know what your rights are or where your rights belong. So to have a rights adviser or someone who can do that sort of thing is important too. I cannot give you an either/or answer. I think what we do is enormously important because it is a solution; it can be a solution and, frankly, I don't see another solution. I gave you a handout this morning. At the back of it you will see how people are becoming more and more vulnerable as time goes on.

So I think it is that important. I also think to have rights is important. I'm going to answer your question in that way because that's my opinion.

**Mr Michael A. Brown (Algoma-Manitoulin):** I want to say how much I enjoyed your presentation. I know, representing a northern rural riding—essentially rural, although sometimes some of my constituents get a little upset when I talk about a city of 14,000 being rural—one of the things, and I think you pointed it out, is the Canadian Mental Health Association, for example, which operates an outreach in the city of Elliot Lake. They provide, not working programs like you do, but day programs and many important, to the people anyway, activities.

I'm concerned—they have expressed this concern to me on a number of occasions—that people, especially schizophrenics, will wander off and there's no way anybody knows where they went, what's happened to them, how they sometimes stop taking their medication, and you really have some great difficulties in making sure that these people have the opportunity and are cared for. I'm wondering if you have some suggestions on how the advocacy side of this, which I think is somewhat important—not somewhat; it is important—and these work-related business opportunities can come together. I'm a little bit unclear on exactly how we mesh those.

**Ms Taylor:** The Advocacy Act that is going to be no more. Hopefully we'll put something in its place. What we hope will be put in its place throughout Ontario—what I'm bringing to you today and what I hope you will



find valuable is the fact that economic development is a way of advocacy. What I say in my tiny, little document here—I made it brief especially—is that we would like to see economic development become the process from which self-advocacy becomes a reality.

I can tell you, Mr Brown, that I work with some people from the north. We have a northern representative on our business council. The north is very interested in getting some economic stuff going as far away as Fort Frances, to Sudbury. They are very interested. We have one who travels down every month just trying to bring the northern concerns. Your concerns of people wandering off, of people not having a place to belong to in society are very valid. That's exactly what that means; that's what that indicates.

It is a symptom that this person is disenfranchised, is disvalued, does not have a place, and so the wandering off and the tragedy. As I was coming here this morning, I saw people on the streets, sleeping on the streets. When I came in yesterday by bus I saw people on the streets and I wondered if they were dead or alive. So some of your northern people, who probably have not been able to find a place in the north, and this goes for the south and eastern Ontario also, probably are some of the people who are sleeping on the streets here or in other urban centres.

Until there is an alternative, another vehicle, a coming together, and we advocate for people by providing places where they can work and become part of our society, not alienated, then I think this is where we begin to cure.

**The Vice-Chair:** I'm sorry, we are out of time. Thank you, on behalf of the committee, for your presentation.  
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#### CONSUMER/SURVIVOR BUSINESS COUNCIL OF ONTARIO

**The Vice-Chair:** Our next submission will be from Diana Capponi, Consumer/Survivor Business Council of Ontario.

**Ms Diana Capponi:** I hope you in particular, Mr Parker, listen well to what I'm talking about, and that'll address some of the issues you raised in regard to why the act is important to our community.

My name is Diana Capponi. I'm here today representing the Consumer/Survivor Business Council of Ontario. We provide hands-on development support to individuals and groups of psychiatric survivors, including schizophrenics, across the province who are interested in participating in the economy. We are really concerned about our high rate of unemployment. We have an 85% rate of unemployment in our community. This unemployment rate would not be tolerated within any other geographical or other community of interest.

I've heard a lot of people speak to this committee; I've been watching the proceedings on TV and I've been present. I guess I should also thank this committee for the opportunity to speak, but I have mixed feelings about this. My understanding, when the Advocacy Act was proclaimed and when the commission was established, was that this commission would be at arm's length from government, and here we are again speaking to lawmakers and to government about the needs of vulnerable

people and the needs of my community and communities of vulnerable people to begin battling all over again to ensure that our rights are protected and that abuses of the systems are decreased.

I've brought some documents attached to my talk for you to look over when you have time. I hope that you do make time, because I see this committee has a tremendous responsibility to a large number of people in this province. Those documents include Yes We Can, and Business (Not Quite) As Usual, which describes the employment strategy, much like Mary Taylor was speaking to, that our community has used to meet our employment needs as well as to increase our economic status.

I would hope that this committee is aware that hand in hand with mental health problems in particular comes poverty. The poverty is often ignored. The focus is on the mental health problem. I see psychiatric survivors and people living in poverty as people who have skills that many of you may not have, and would not survive the circumstances in which many psychiatric survivors live.

I've listened to the presentations from A-WAY Express, I listened this morning with Abel, I've heard David Reville's talk in regard to the Advocacy Act and I support all those submissions, although when I'm sitting at home and watching TV and hearing deputations much like the Ontario Psychiatric Association, I'm amazed that my TV is still in one piece.

The Ontario Psychiatric Association talks about alliances between patients and doctors. I would suggest that this committee needs to speak to more patients, in particular in the mental health system, and get their viewpoints on this "alliance." This committee has to be aware that there are conflicts of interest here that we're talking about and that there are billion-dollar industries out there, making money and creating jobs through our pain. I wish I had a job that I could work at and not have any accountability or responsibility for the work that I do.

I've listened to Mr Clement speak many times—he's not here today, unfortunately—about the notion of moral responsibility. If we have an Advocacy Act, if we have patients' rights advisers, then we're going to get away from the community and the family's moral responsibility. Here are some examples of the lack of moral responsibility that I and people I care deeply about have suffered.

I'm a 43-year-old woman. I come from a really extremely violent home situation. I've had past drug addictions, I've had several pregnancies and I have serious and severe health complications. The last institutional setting I was through was within the Ontario mental health care system. I've also travelled a lot in my lifetime and I've seen poverty and degradation, but I've never seen poverty and degradation the way it is here in the province of Ontario.

I've lived in rooming and boarding homes, homes that I was discharged to as part of a mental health care system. I've witnessed people being punished and thrown into the streets. I've witnessed people losing limbs due to frostbite because service providers and professionals had deemed them uncooperative and uncompliant. I'm used to lice being a daily part of life, every day using Kwellada shampoo. I'm lucky I have so much hair today.



We would like to believe that community and social services and families are natural advocates for vulnerable people, and yes, often they are, but not always. Let's not be naïve and forget that often families are the root cause for why people end up in the system in the first place. I'd like to challenge any member of this committee who had taken a life path different from the path that their families would want you to. What have been those consequences? If you have money, if you have education, the consequences may not be so terrible. If you have a disability, if you have no money, if you have no education, families can often be the enemy.

I want to give you a few examples of what I see is a lack of moral responsibility, and taking away the Advocacy Act will do nothing to help these circumstances.

I lived, when I was discharged from a provincial psychiatric hospital, in an infamous rooming and board home where unfortunately 65 people with mental health problems were housed. The rent was deemed strictly on the basis of their income. Meals were arranged that included stale bologna sandwiches—I ate them a lot—macaroni and cheese, Puffs and corn flakes. The house had lice, scabies and mice, and here were people with disabilities living in this situation, with a community filled with “moral responsibility” watching.

Occupational therapists came daily, public health nurses came daily, doctors came daily, adult protective service workers came daily, the general welfare workers came daily and FBA workers came daily, yet for years no one took the moral responsibility and addressed the abuses and in fact the deaths that went on in that house. One man by the name of John, a developmentally disabled man, developed a flu bug. The flu bug turned into pneumonia and John died. John died with a number of professionals responsible for his care. John died in this home, in a community that would like to assume it has moral responsibility. That moral responsibility was met at the inquest into John's death, and here we are again, today still, trying to fight for rights and to stop the abuses that go on that could lead to deaths of people like John.

Another woman in the home getting raped—no locks on the door. Anyone could come into the home. Anybody on the street could enter the home and do whatever to whatever resident there, and do you know what? The residents could call the police and complain and could complain to workers, but if you have a mental health problem, you're usually not listened to.

I'll tell you a story about a young woman by the name of Jeneace, who had been sexually and physically abused. She was deemed developmentally disabled at a very young age. She was placed in foster care at the age of 11. Her foster father repeatedly had sexual intercourse with her. This was the year prior to him being named the foster father of the year of an association. When this woman was pregnant, she developed leukaemia. The minute the baby was born, the child was placed in care and she was sent to hospital for treatment of her leukaemia.

The treatment was very extensive and the woman almost did not survive the treatment, but she did and then tried to get her child back. Trying to regain custody of the child was almost impossible for her because of her disability. Her foster father and mother were also trying

to gain custody of the child, and at this point Jeneace decided to name who the father of her baby was. Ultimately, Jeneace lost full parental rights to her child.

Within two months of having lost rights to her child, the leukaemia returned. She was aware of the ramifications of not having extensive treatment again. She didn't want to be in the hospital. She didn't want to go through the pain and suffering she had gone through. She didn't want her family members coming and harassing her on a daily basis at the hospital, and she certainly didn't want to see her foster father again.

The response of the hospital at that point was to form Jeneace against her will. She was deemed incompetent. After a day and a half of being held in physical restraints in hospital, I was able to see Jeneace. Nobody had advised Jeneace of her rights. Nobody had spoken to her in a way that Jeneace understood. A legal aid lawyer came. Finally, when she was aware of the fact that she was entitled to representation, a legal aid lawyer, with very little understanding of the Mental Health Act or of the review board that takes place in hospital, came to supposedly take care of her rights.

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His first statement to her was, “Why don't you reconsider and do what the hospital wants?” I was shocked. I pointed out to him that he was there to meet her needs, and we went through the review board process together. Jeneace was found competent at that review board hearing, but prior to that time, she had to succumb to a spinal tap because she felt that was one way she could get free use of her arms and legs. Where was the hospital's moral responsibility in that case?

Finally, I want to give an example of a family member of mine, my own brother. My brother was raised in the same home I was, and he wasn't such a great, nice, likable guy, even when he was healthy. My brother was diagnosed with AIDS and dementia set in in the latter stage of his life. He was living in a room at that point, with dementia, with jars of feces and urine, his clothing all in bags, bugs flying through the air. When he walked the streets, people stared at him. People refused to give him service. He looked like he was dead. He would have seizures and blackouts consistently.

Tenants in the building complained about his presence. The smell of his apartment just permeated the whole building. He was arrested several times. He would go to the airport and try to get to Jamaica without any ID or without any money. He couldn't understand why it was so difficult for him to be able to leave this country. Police would arrest him. They would call his family and they would ask for us to come pick him up. We would ask that a doctor go and visit my brother in a jail setting and determine his competency. Well, the doctors didn't want to do that, including my brother's own doctor. It took too much time; they weren't prepared to travel all the way to Etobicoke. The police certainly didn't want to hold him, because he was too disgusting to look at.

Finally, because of our name—the Capponi name has some clout in the mental health care system—we were able to get my brother formed and brought into hospital. Once his dehydration was taken care of and he was deemed medically fit, even though he was in the final



stages of AIDS, he was deemed competent to make the decision that he didn't want any intrusive medical stuff happening to him, and we all agreed with that.

However, we were very concerned about my brother's mental health status. The psychiatric ward certainly didn't want a stinky, dying man on their unit. We had to do a horrific amount of advocacy to ensure that my brother did stay in hospital and avoided dying frozen to death on the streets. My understanding, in dealing with public health workers, is that a lot of people with AIDS develop dementia and that part of the dementia is a lack of impulse control. Folks end up in jail, dying in jails. This is unacceptable. Where is the moral responsibility?

My brother was treated so horribly in hospital. The last two months of his life he was secluded, kept in a room far back from the rest of psychiatric ward; the staff of the ward would sneer at us. Really, in my brother's case, he was in hospital against their will, not against his will. He was not encouraged to participate in programs. His diapers weren't changed. He had genital lesions, and he would sit for 10 hours and not be changed. This is a hospital with a good reputation here in the city of Toronto. The day he was finally transferred to Casey House, to a place where he could get decent care—I can't even talk about that day without getting emotional. It was gross.

I want to remind this committee, especially Mr Parker, who has asked the question, why is the Advocacy Act so important to my community, for the reasons I've already stated, and maybe I'll just state a few more cases. The head of psychiatry at the University of British Columbia—there's a big case. There was an esteemed doctor whom everyone trusted, who probably talked the same line as the Ontario Psychiatric Association. He talked about alliances, he talked about trusting doctors, he also talked about distrusting clients and distrusting patients. How many women did he torture and abuse before he was brought to trial? How many women were ignored by other so-called professionals?

I also want to talk about homes for special care. This government made its first announcement that the Advocacy Act was going to be repealed and that finally trust would be back where it belonged, in the hands of families and in the hands of the medical profession. In the very same paper, in the *Toronto Star* that day, there were criminal charges pending at a home for special care where staff were found to be spending the pin money of the residents living in that home. Where was their moral responsibility?

It has been proven and well documented that the level of vulnerability increases the prospect of a person being abused. That doesn't exclude doctors, service providers and hospital workers. We also need to think about why people end up in the system, especially in the mental health system. When we look at women in particular, why do women end up in the mental health system? I would suggest that often—not always, but often—it's because of families. Yet we're supposed to trust families. This government today does not trust doctors. We're revamping the whole OHIP system because the government talks about doctor fraud. Yet my community, a

vulnerable community, is told to trust doctors and to trust our families. This to me is really schizophrenic.

A country, a province or a state is judged by others and historically by how it has treated its vulnerable peoples. I implore this committee to think about the proposal submitted by David Reville. I implore this committee to think about the conflict of interest inherent in giving hospital staff the role of telling people their rights. I remind this committee of the public trustee's office and the auditor's complaints of how public trustees' offices have been run, some of the flagrant stuff that's gone on in those offices. To say that hospital staff should tell us what our rights are is tantamount, to me, to having no rights.

The business council and our member businesses have witnessed at first hand the impact of role modelling and empowering, when members of my community see other members of their community coming from their experience, speaking up and doing well. Our community is fed up with going to people who are paid to take care of us. We want to go to members of our own community when we need to. For us, "your best interests" are words that create much anxiety, panic and fear. I don't want anyone to say what's in my best interests, and if I'm at a point in life when someone does have that ability to say what's in my best interests, I would hope that individual would come from a community or an experiential base such as mine.

I want members of this committee to think about putting trust back in the hands of the families. What happens when families die? What happens when your parents die? Who's there to care for your child? Presumably, all families would want their child to have the ability to care for themselves. If they are not able to care for themselves, you would want the best person there to represent your child.

My community talks about poverty of soul, the loss of hope and the loss of opportunity, and total dependence on other people, people who do not understand where you come from, where you've been and what you're bringing with you. I suggest that members of all disabled communities have expertise, members of disabled communities have been service providers, members of disabled communities understand the barriers when trying to implement rights.

When this government came to power it claimed that the Common Sense Revolution would not impact disabled persons. I witness this impact daily. Unfortunately, we are the have-nots. I don't believe this government is a caring government; I don't believe this government cares about my community. You're setting out on a fiscal agenda that does not allow for human rights and does not allow for moral responsibility. If Bill 19 is enacted without a component of self-help advocacy, I believe this government is setting up many, many thousands of people in the province of Ontario to be abused. Thank you.

1050

**Mr Ron Johnson (Brantford):** I want to thank you, Ms Capponi, for your presentation. It certainly contained a number of suggestions and ideas and thoughts that I know we're all going to take very seriously. I want to say that by virtue of your presentation today, you have



proven yourself to be a very strong advocate for the people you represent, some of the underprivileged and some of the vulnerable. You should certainly be congratulated for your commendable efforts in that regard.

I want to say at the outset that this government does believe in advocacy. In fact, we're very strong proponents of advocacy. The problem we have is that we disagree with the approach to advocacy that the previous government took, and that's really where we're coming from. A lot of people have sat in the chair you're sitting in, have come forward, including, I might add, Ms Taylor before you, who understand that advocacy isn't about government bureaucracy, that you can't provide advocacy service through a government bureaucracy, that it's the grass-roots people, the people in the communities such as yourself, who can best do that. We recognize that.

What we want to do is come up with a plan and some suggestions, through ideas we're getting from people like yourselves and Ms Taylor before you, to foster that, to help grow. We believe we all have a responsibility to advocate on behalf of those who are less fortunate, and we want to tap into that and we want to use some of the suggestions we're getting at these hearings to come up with a solid plan to do that.

I know that a lot of the things we're looking at and things we've heard in the past are that government's role in terms of advocacy could really be defined as support services, possibly providing some training for those who are going to provide that kind of advocacy work. That's really where we're coming from. It's the approach. We support advocacy in a big way; we're behind it. We just feel that government can't do everything and government doesn't necessarily achieve the best results. The best results come from people like yourself, and that's really what we're trying to foster.

**Ms Capponi:** Thank you for your comments. I'd like to agree with you, but I ask you, if that's so, if government doesn't really belong in the business of advocacy, why was the act repealed? Why is the commission almost dead? Why would this government suggest that staff in hospital advise patients of their rights? Inherent conflicts there, inherent. Are we all so la-la that we think all the staff in hospitals are kind, generous, wonderful people, that evil people are only outside of hospital? These are the kinds of issues that the government needs to do some more learning about and speak to a lot more people.

**Mr Ramsay:** Thank you, Diana, for your presentation. The words coming from my colleague on the government side are very nice, but I can understand why you feel abandoned, because as the government has decided to repeal the Advocacy Commission, it has not, as you know, brought forward anything to replace it, has not made any commitment, such as has been proposed, that maybe \$3 million might be able to do the job, and to work with people in the community; just saying that maybe some time after this process, it will come up with something.

I agree with you. I do not think that \$3 million is too much to put into the advocacy community of Ontario to ensure that there is coordination, to ensure that there are quality standards, to make sure that there is the adequate training for people to do the job and to make sure in the

end that there's accountability, so that we know vulnerable people in Ontario are being protected.

I just want to tell you from the Liberal Party, the official opposition, that we will be pushing the government to bring in a replacement system.

**Mrs Boyd:** Thank you very much for your presentation. Did you regard the Advocacy Commission as government? I understood what you were saying as quite the opposite.

**Ms Capponi:** No. I was told it was supposed to be hands-off, yet there's an election and the commission is gone, and here we are yet again. It was sort of outside of government, but was it really? My understanding is that for the last few months of the commission, they were frozen from doing anything, so that's like a façade.

**Mrs Boyd:** Yes. They didn't really get a chance to do anything except the rights advice, which your examples show us very clearly is needed. That's one of our concerns, that the rights advice is not there.

The other aspect: It's all very well to say, "Well, you're a great advocate," but you know what you went through. You had no right of entry, you had no right to access to records, you had no authority whatsoever on which to act, even when you were a member of a family. Your story about your brother ought to really give us pause because it shows us quite clearly that the medical profession doesn't even listen to families.

**Ms Capponi:** That's right.

**Mrs Boyd:** And without the kind of empowerment that's there, it's very difficult to really act on behalf of someone, isn't it?

**Ms Capponi:** Yes, it is. I've got to say in terms of myself being a powerful advocate, how unfortunate for the thousands of other people out there who don't have the skills or haven't been where I've been in order to be able to get my brother to stay in hospital. What about all those other folks who don't have advocates, right? How can we train our own communities to advocate for ourselves? How can we support that? How can we use members of the disabled communities to be rights advisers? Those are the kinds of things that the Advocacy Commission is suggesting in its much toned-down proposal and I certainly urge that this committee look at that very seriously. Let's put a per capita on the \$3 million compared to how many disabled folks there are in this province; a very small amount of money we're talking about.

**Mrs Boyd:** Quite frankly, even the \$18 million was a very small amount of money, wasn't it?

**Ms Capponi:** Yes.

**Mr Marchese:** Ms Capponi, I just want to thank you for your presentation. Some of us are very aware of all the work that you've done in the field of advocacy for vulnerable people. Mr Johnson says the government's role is to provide support services to people. If that's what they're doing, we're in trouble, because they're cutting away at every imaginable support service one can think of. So if they don't provide the advocacy and at the same time they reduce all the support systems for people like yourself, we have a problem.

It is our view that the government has a responsibility to advocate on behalf of vulnerable people, because if



they're not doing it, then we're at the mercy of all of the problems that you spoke about.

**Ms Capponi:** That's right.

**Mr Marchese:** Because who will take care of those people who you mention in your brief and countless other people mentioned as great examples of how systems abuse people? They no other recourse. You take the rights advisers away and who is left to deal with them? As they say, caring families and the good doctors that are there in the system. You pointed out that, from time to time, the good families are not there and that, from time to time, the good doctors are not there either. Then what are you left with? You're left with the government saying: "Sorry we can't help you. It's not our job. Sorry we have to cut because the budgets say we have a serious deficit, so what can you do?" So they say they like advocacy and support it, but they don't really mean it.

I just wanted to agree with the position paper you put forth and I hope the government listens to people like yourself who speak about other vulnerable situations. You're one of the people who survived. They don't understand that. They think that everybody out there is probably like you. But you survived difficult situations. Not many are able to survive those situations. It's for that reason that we needed a commission that does education, training, and deals with systemic problems, and that we needed rights advisers to deal with the abuses you spoke of. Thank you for your presentation.

**The Chair:** On behalf of the committee, thank you, Ms Capponi, for your presentation.

#### LEARNING DISABILITIES ASSOCIATION OF ONTARIO

**The Chair:** Our next submission is the Learning Disabilities Association of Ontario; Sharon Bell-Wilson, assistant executive director. Welcome.

**Ms Sharon Bell-Wilson:** I talk fast. Thank you, Mr Chair and members of the standing committee on administration of justice. The Learning Disabilities Association of Ontario is pleased to be provided the opportunity of making a presentation to you regarding Bill 19.

LDAO is a voluntary, non-profit, charitable organization that has been the central voice for persons with learning disabilities, some 10% of the total population, in Ontario since 1964. LDAO's mission is the attainment of a society in which persons with learning disabilities are enabled to reach their full potential. LDAO is the pre-eminent advocate on behalf of persons with learning disabilities in the province. Through our 48 local associations, we work tirelessly to protect the rights of persons with learning disabilities in all walks of life.

1100

In all civilized societies there is a desire to protect the most vulnerable members. These vulnerable individuals tend to be children, people with disabilities and others who have been disadvantaged by their situation. In many countries such protection takes the form of a paternalistic charitable system, where persons who are vulnerable rely on the philanthropic impulses of the less vulnerable. Such a system does not usually allow for the process of empowerment and enablement whereby vulnerable persons gradually become less vulnerable.

Many people over the past decade have concerned themselves with creating such a situation for the vulnerable persons in Ontario. Foremost among those was the late Father Sean O'Sullivan, who in his report *You've Got a Friend* proposed a formalized advocacy system for Ontario.

In 1992, LDAO presented its response to the original Advocacy Act, Bill 74, at which time the primary focus was the definition of vulnerable persons, the role of the Advocacy Commission, and the issue of awareness and training. LDAO participated in the process of establishing the Advocacy Commission and had high hopes that, once the process was fully in place, persons with learning disabilities would be enabled to take control of their own lives.

Who are these people with learning disabilities? Learning disabilities are neurological in nature and they are manifested in difficulties in any of the following areas of functioning: visual processing, auditory processing, fine motor processing, vocal expression, space orientation, time management, balance, coordination, social dysfunctions and setting priorities. Some common characteristics of learning disabilities include difficulties in reading, writing, spelling or mathematical abilities; poor short-term auditory memory, which means they hear inaccurately; directional confusion between left and right or east and west; sequencing difficulties, such as alphabetical order, months of the year, seasons, tables, lists of instructions and so on; takes spoken and written word literally—does not understand nuances.

It is not always easy to identify persons with learning disabilities. For example, an individual who is skilled in language may find anything to do with mathematical calculations, such as balancing a cheque book, a virtual impossibility. By the same token, a brilliant scientist may be completely unable to spell any word.

Research results indicate that learning disabilities affect at least 10% of the general population and cut across all ethnic, linguistic, religious and socioeconomic boundaries. However, it is worth noting that learning disabilities affect males four times as frequently as females. For example, out of every 10 persons identified with learning disabilities, eight will be male and two will be female.

Talking about vulnerability and learning disabilities for a minute, one might ask what is it that makes persons with learning disabilities vulnerable? Consider the following:

A disproportionate percentage of young offenders, between 60% and 80%, have been or may be identified as having a learning disability.

Learning disabilities are implicated in at least 50% of all teen suicides and suicide attempts.

Adults with learning disabilities are more habitually unemployed, often unable to hold a job for more than three months.

Given these examples and the characteristics of persons with learning disabilities previously outlined, there should be no doubt as to vulnerability or disability. The fact is that persons with learning disabilities have difficulties learning and applying the rules and conventions which govern our daily lives. Therefore, their vulnerability and



disadvantages stem both from their innate characteristics and from society's response to them.

You only have to review the report of the Ontario government's interministerial working group on learning disabilities to note that there is significant systemic discrimination against persons with learning disabilities. Since that report was published, things have not improved and the inequity continues. With the repeal of the Advocacy Act, it is now unknown whether vulnerable persons, including persons with learning disabilities, will have access to a process for advocating on their own behalf.

Bill 74, with its sole emphasis on advocacy, was about 15 pages in length. Bill 19, a document of more than 100 pages in length, mentions advocacy about three times in total. It would appear that there is some disparity as to the level of importance placed on advocacy, despite the percentages of vulnerable persons in Ontario. One cannot help but wonder to what degree the need for advocacy was comprehended prior to the blanket repeal of the act.

It would appear that the main thrust of the repeal of the Advocacy Act is the elimination of the Advocacy Commission. Perhaps the Advocacy Commission and the proposed process were not the best or most effective ways of addressing the advocacy needs of vulnerable persons; however, we strongly urge that Bill 19 be amended prior to third reading by indicating what is going to be available to vulnerable persons in meeting their advocacy needs.

To that end, LDAO would like to offer some recommendations for alternatives for vulnerable persons in a post-Advocacy Act era, the first of which is the strengthening of the Human Rights Code. The Ontario Human Rights Code protects persons with disabilities from various forms of discrimination and guarantees accommodation rights for persons with disabilities. The 1989 guidelines for accommodations should become part of the code or at least a regulation under the act.

The second is the enhancement of the advocacy process within the Human Rights Commission. For many, the process of filing a human rights complaint is an exhaustive, frustrating and subsequently unsatisfactory process. There are unexplained delays that resulted in complaints remaining unresolved for years. In order that the Human Rights Commission route may be deemed a viable route for vulnerable persons, the necessary resources must be allocated to the Human Rights Commission to reduce the backlog of current cases, while ensuring that new complaints move smoothly and steadily through the system. This action would clearly demonstrate a commitment to protecting the rights of vulnerable persons.

Third, the introduction of the Ontarians with Disabilities Act would be modeled after the Americans with Disabilities Act, which is considered "the most comprehensive and far-reaching piece of anti-discrimination legislation for persons with disabilities in the western world." This act would provide the government with an excellent vehicle in which to demonstrate its willingness to help vulnerable persons exercise their rights. ODA has the potential to be far-reaching in its protection as it relates to persons with disabilities in Ontario, enjoying equal opportunity protection under the law in all aspects

of their lives. The process began with the introduction of Bill 168 in the last session of the Legislature. Although not perfect, it represented a good beginning. LDAO urges prompt action on reactivating the ODA.

The balance of Bill 19 focuses on the proposed amendments to the former Consent to Treatment Act and Substitute Decisions Act. While we regret the elimination of the process for the provision of rights advice and the anticipated greater independence for profoundly disabled individuals, we also understand the concerns of those who viewed these acts as anti-family. We know that there will be many others who will comment on these proposed changes in detail. We have chosen not to do so in order to maintain the focus on the advocacy needs of persons with learning disabilities. However, we do wish to reiterate the importance of ensuring that all those who work directly or indirectly with vulnerable individuals under any of this or other legislation are appropriately trained in recognizing and understanding the needs of persons with learning disabilities.

In conclusion, for persons with learning disabilities, LDAO has tried to meet the advocacy requirements to the best of its ability. This includes systemic advocacy, such as today's presentation on behalf of persons with learning disabilities in Ontario; individual advocacy, which involves accompanying families of children with learning disabilities and/or adult consumers who require assistance in the school, in the workplace, or in dealings with various other bodies; self-advocacy training for consumers, which involves formal training and completion of a workbook as a means of helping consumers advocate for themselves. Understandably, LDAO, with limited human and financial resources—I will note here that we are 80% to 90% funded through public donations—has difficulties in meeting the growing demand for advocacy services from persons with learning disabilities. It was therefore our hope that the Advocacy Act would have complemented our efforts and provided the necessary support to other vulnerable persons in Ontario.

LDAO fully intends to continue providing advocacy services. While LDAO regrets that the Advocacy Act did not have a chance to demonstrate its worth, we remain hopeful that some government initiative will be enacted to inform, educate and protect vulnerable persons in Ontario, including the nearly one million persons in this province who have learning disabilities.

A former US senator once remarked, "People don't believe that government knows how to help or wants to bother." For the sake of all vulnerable persons, and in particular persons with learning disabilities in Ontario, LDAO urges this government to please bother.

1110

**Mrs Caplan:** An excellent brief. I really appreciate the points that you've made. The legislation does not require individuals to be told when they are found to be not able to understand and appreciate—that's the terminology for consent. We've heard from a number of the professional colleges and others who feel it shouldn't have to be explicit in the statute. We've also heard from many others that they feel it should be in the statute. Some suggest an amendment to the regulated health professions legislation that would allow the colleges to set guidelines



for how people could be informed. Do you have any view on which is a better approach, whether you'd like to see it in statute or guidelines under the regulated health professions legislation?

**Ms Bell-Wilson:** I guess my comment would be that really anything that places the need for education and informing as strong as it can possibly be is what we would strongly encourage. Obviously, being representative of an organization that for so many years has had such a fight in trying to get people to understand, first of all, what learning disabilities are and that it's not a bad thing to have a learning disability and that it deserves some type of respect across the board, we would be a strong proponent or strongly endorse any legislation at its full extent that would encourage any type of training and education.

**Mrs Caplan:** In fact the intention would be to encourage and require communication with individuals who have been told that they're not able to make their own decisions and also to inform such individuals of their right to appeal to the consent and capacity board.

The reason I'm asking this question at this time is we have some new information that arrived today in a presentation to the committee. The College of Chiropractors have said, and I'm going to quote from their letter:

"We are concerned, however, about a suggestion made during the second reading debate that the Regulated Health Professions Act should be amended to require colleges to issue practice guidelines or standards dealing with notification to patients about their rights under the Health Care Consent Act. We do not think such an amendment is necessary or desirable."

My concern is if we don't do it under the Regulated Health Professions Act and it's not in the Health Care Consent Act, how are we going to be certain that people are aware of their rights? And who should have this obligation since this legislation removes all requirement for rights advice?

**Ms Bell-Wilson:** Inasmuch as we are also very strong proponents of self-advocacy, we would certainly suggest that individuals be as aware of whatever it is that they need to be aware of, what their conditions are, what their rights are etc so that they can then know which directions they may wish to go. I think oftentimes we make assumptions about the incapacabilities of individuals if they have a disability, regardless of what the disability is. "Oh, they cannot think for themselves." They can think for themselves if they are given the opportunity to think.

**Mrs Caplan:** I don't want to put any words in your mouth, I just want to make sure I understand what you're saying, and that is, you would support clarity in the legislation that would encourage communication so that patients would be aware of what was happening to them?

**Ms Bell-Wilson:** Yes.

**Mrs Caplan:** Just to pursue this a little further, there was an article in the Toronto Star, dated February 18, that was a review of complaints to the College of Physicians and Surgeons. I just had a chance to review this this morning and it talks about the number of complaints that related to communication breakdown. It says here, "The head of the college's complaints committee says a doctor's inability to communicate is often the underlying

cause of a complaint." Certainly we'd like to see complaints reduced. So your point about education and training and need to understand this legislation has been enforced as well by the verdict of a coroner's jury in the Clemens case.

Very simply, do you think this legislation should have a clause in it stating the obligation of a person who does the evaluation, the professional, to have to tell a patient that they are not found capable of making their own decisions and also of their right to appeal, to encourage that communication and education? Do you think this legislation should have a clause in it that requires that?

**Ms Bell-Wilson:** Again, speaking on behalf of the population that I represent, I would think that that is paramount.

**Mr Marchese:** Thank you, Ms Bell-Wilson, for your presentation. I want to comment on some of the suggestions you made and other comments that you made here. With respect to your suggestions around strengthening the human rights, just as a reminder, this government repealed the Employment Equity Act, which we felt very strongly about. It was our way of saying we need to restore fairness to people who otherwise are not getting fairness in the workplace. We have a different view of fairness on both sides of this room.

They said they would bring back an equal opportunity plan. We never knew what that plan was. They talked about this plan but never resurrected it. I'm afraid it will never be resurrected. They now talk about they have something for advocacy in place. We don't know what that is. We'll never know, except we should help volunteers, I suspect. I don't know how they're going to help volunteers.

You talked about strengthening human rights, and they said they were going to put some money into strengthening human rights. I can bet my right hand there will be very little that will go into the Human Rights Commission. They won't put a cent into it. So as much and as useful as some of the suggestions are, I'm not sure that we're going to see anything.

With respect to the Human Rights Commission, it's driven by complaints. That's a problem with it in the first place, because we have to wait for someone to come and tell us we've got a problem. Then we've got to wait a couple of years to resolve it. So it's a problem to rely on the commission to deal with individual and systemic abuses. The suggestions are useful but we won't get much, and I'm not sure that's the solution either to some of the things we've talked about here today.

In terms of some of the other comments that you made, you pointed out that advocacy complemented the efforts of your organization. That's what we felt as well. We believe we need an organization in place, at arms's length, that has authority to deal with the issues of training, education and to deal with systemic problems. If you don't have that, all of our efforts, the few little dollars they might put, which I doubt, will be lost, because it won't be coordinated. There will be no way of keeping record or track of anything that we do.

I agree with the US politician who remarked, "People don't believe the government knows how to help or wants to bother." Because we don't hear from the



government what they propose and because I believe they have an obligation to tell us what they propose, I am not quite certain that I want to believe what they say about, "We have something in place." But I agree with you that we should know what they propose as a way of dealing with the repeal of the Advocacy Act altogether and the commission.

**Mrs Boyd:** Do you think that the level of disability for many of the people that your association serves would make them incapable of understanding what was being proposed in terms of medical treatment or make them incapable of managing their own property?

**Ms Bell-Wilson:** If you recall, in my comment very early, as I was trying to describe persons with learning disabilities, I talked about taking the spoken and written word literally and not understanding the nuances. If you take that and couple that, for example, with the situation with regard to young offenders, we make certain assumptions when a person is standing before an authority figure and various things are being said. For persons with learning disabilities, the words are being said but they're not being processed the same way that we would assume they would be understood. So they're not picking up on the importance or the emphasis on certain statements or certain words etc. Does that make them vulnerable? Very much so.

1120

**Mrs Boyd:** So part of the advocacy function that you would see for the particular population you're concerned about would be the ability to apply to have someone declared incapable of making important decisions when that kind of disability presents itself?

**Ms Bell-Wilson:** First of all, I think it's very important that we understand what the person understands. You're saying to them, "This means your situation is" whatever, but making sure, and maybe it means constant repetition, constant reinforcement etc, to make sure that they do understand, and then if need be, that they have someone with them as an advocate if they are not going to be capable of advocating solely on their own.

**Mrs Boyd:** So in terms of consent to health treatment, for example, saying the words would not necessarily ensure that the person understood the consequences of treatment or lack of treatment.

**Ms Bell-Wilson:** No, they wouldn't, not a person with a learning disability, because as I said, they hear the words. The issue is obviously not their inability to hear but their inability to process it in a way that is understood, as you and I are speaking. For persons with learning disabilities, no, that's not necessarily going to be the case.

**Mrs Boyd:** So then I take it that both individual advocacy and systemic advocacy are needs that you see. Systemic would have been the primary thing in the Advocacy Act.

**Ms Bell-Wilson:** Very strongly.

**Mr Ron Johnson:** Ms Bell-Wilson, I want to thank you for your presentation today and I want to thank you as well for taking part in the stakeholder consultations that we held. I know that you had some very good things and positive things to say to us during those consultations.

I want to make a comment here with respect to the Human Rights Commission, because that's something you said that we need to strengthen, and we agree with you on that. In fact we're going to strengthen it by making it more efficient and more effective. That's really the goal of the government, and we're going to be looking at a number of ways to do that.

We agree, actually, with Rosemary Brown, former NDP member of federal Parliament, who says that throwing more money at the problem is not the solution to fixing the Human Rights Commission. She says that herself, despite what my colleague Mr Marchese thinks, and I happen to agree with Ms Brown that the answer isn't throwing more money at the problem.

I want to say too that with respect to employment equity—and you're right, Mr Marchese's right, we did repeal that—that discrimination is against the law under the Human Rights Commission anyway. I don't see how he tied the two together, quite frankly.

I want to talk briefly about a line that in your presentation which I found to be absolutely tremendous: "The LDAO is the pre-eminent advocate on behalf of persons with learning disabilities in the province. Through our 48 local associations, we work tirelessly to protect the rights of persons with learning disabilities in all walks of life."

I want to congratulate you and all 48 organizations for the fine work that you do in advocacy and I want to suggest to you that that's the goal of this government, to foster that kind of support in advocacy work. There's a great deal to be learned, I think, from groups like yourselves, and we look at putting in place some support mechanisms to help you with that.

I'm just going to briefly say something too. You mentioned the O'Sullivan report, and I want to quote you a piece of that report. This is what Mr O'Sullivan said in that report: "Primary responsibility for advocacy must remain with us as individual citizens, as families, as friends and as neighbours of Ontario's vulnerable population." He goes on to say, "Primary responsibility for advocacy education and the development and support of advocacy services is the proper role of government."

What I would like from you, explain, if you could, what your view is of providing the education services and the support that advocacy services and agencies like your own would use. What's our role as government in that regard?

**Ms Bell-Wilson:** The role of the government would be to complement the work, as I indicated in my report, that organizations such as ours are performing. One of the reasons I threw another little stat in there was to say: "We cannot do it all. We do a lot, but we cannot do it all." We don't have a lot of money. As a matter of fact, we have a program that right now has to do with some form of advocacy, the advocacy training I mentioned our organization is involved in doing for adults with learning disabilities. This funding proposal seems to be on hold at this point in time, so right now there are people we want to help that we can't help. So if you say, "What can this government do?" one of them would be to release the money.

The second one would be to complement in terms of—if we move past the commission issue for a minute, there



were other things that were suggested, like the training, training of persons to be advocates, but ensuring that the training is broad-based enough so it covers all situations or all possibilities. Again we put up our hand and say, "Don't forget persons with learning disabilities when you're talking about persons with disabilities." We are very strong in our belief in that type of training and that being a very major component in the area of communication.

**Mr Frank Klees (York-Mackenzie):** Thank you for your presentation. I just want to take the few seconds left to clarify for the record that we are very supportive of ensuring that advocacy does take place effectively in this province. It's unfortunate that members of the opposition on this committee repeatedly characterize this process as one of ineffectiveness and that they don't believe the government will in fact do anything.

I just want to assure you and others who have come before this committee that we are not here to waste your time, that we are here to listen to you, to get your positive input, and that we will—we will—act on those recommendations that we feel we can legitimately put in place in this province for vulnerable people.

Thank you for taking the time, and I regret that these proceedings are being characterized as anything but very meaningful.

**The Chair:** Thank you, Ms Bell-Wilson, not only for your presentation but for this very attractive brochure and folder contained therein.

**Ms Bell-Wilson:** We aim to please. Thank you.

**Mrs Johns:** On a point of privilege, Mr Chair: I have a copy of the letter from the chiropractic association. Could the clerk—

**Mrs Caplan:** It was tabled today.

**Mrs Johns:** Was it? Did you guys get it?

**Mrs Caplan:** Yes. You should have it. I got it in my package. I think everybody received it.

**Clerk of the Committee (Ms Donna Bryce):** It was sent to your office.

**Mrs Johns:** I haven't been there yet. Thank you.

#### ONTARIO ASSOCIATION OF NON-PROFIT HOMES AND SERVICES FOR SENIORS

**The Chair:** Our next presentation is the Ontario Association of Non-Profit Homes and Services for Seniors, Carol Shaw, president. I understand that your brief will be coming in writing, so we will be obtaining that. I'd ask you to identify yourselves for the purposes of Hansard.

**Ms Carol Shaw:** Thank you, Mr Chairman. We do apologize for the missing brief. Maybe we call it a cost saving for us in the end, although it wasn't intended to be that way: We will not be paying the courier charge. We had couriered them to you last week, but apparently they didn't arrive on time. We apologize, and as soon as they are here, we understand they will be given to you.

I would like to introduce the group I'm with. First of all, I'm Carol Shaw, president of the Ontario Association of Non-Profit Homes and Services for Seniors; OANHSS, in other words. With me are Michael Klejman, our executive director; Paul O'Kafka, a past president of OANHSS and also the executive director of St Joseph's

Villa in Dundas and a member of the interim advisory committee of the Attorney General regarding the Substitute Decisions Act; and Margaret Ringland, a member of our association, the director of regional relations and professional services for the association.

**1130**

I'd like to tell you, first of all, a little about our association. For 75 years the Ontario Association of Non-Profit Homes and Services for Seniors has represented non-profit, long-term-care providers in Ontario. OANHSS itself is a non-profit charitable corporation comprised of municipal and charitable organizations which operate a variety of programs and services for seniors.

Currently, OANHSS has over 200 members who provide services to 140,000 seniors across the province. Its members operate a full range of services, including homes for the aged, non-profit nursing homes, seniors' housing and community support services. In some communities, OANHSS members are the primary providers of both facility-based and in-home services. They pioneered many of the concepts that are so central to long-term care today: supportive housing through private home care, group homes and satellite homes; adult day programs; respite care and emergency response units to assist caregivers in the community; in-home community programs such as Meals on Wheels; and the idea of partnership and cooperation with community-based agencies.

The association offers its members educational and information services, as well as group services for purchasing, insurance, employee benefits and consulting. It also supplies support to its members by responding to important issues, including legislation, such as Bill 19, that materially affects its members.

During the 1992 hearings on the Consent to Treatment Act, the Substitute Decisions Act and the Advocacy Act, OANHSS generally supported the attempt to address issues such as loss of personal control over important decisions that may affect vulnerable, disabled or elderly persons.

However, the association also anticipated some practical problems in the application of the rigid, formal processes entrenched in the legislation. We were especially concerned that the legislation did not recognize the contribution of individuals, families, caregivers and agencies that care for and are relied upon to seek the best for those who depend upon them.

For these reasons, our members are pleased with many of the changes Bill 19 has introduced. They address our concerns about the rigidity of the processes included in the legislation and reaffirm the important role of family and friends in giving support to vulnerable people.

As well, we appreciate the proposals that alleviate the complexity that threatens the ability of health care providers to implement the intent of the legislation. In particular, the association supports the following mechanisms, which you'll hear about today, that reduce legislative barriers to care created by the Consent to Treatment Act and the Substitute Decisions Act. We also support the elimination of the Advocacy Commission and the Advocacy Act, as these two components have been taken to the extreme in both the act and the practice.



**Mr Paul O'Krafka:** Mr Martiniuk and members of the committee, it's a pleasure to be back here again and to see some very changed legislation. We've followed this legislation for the last three or four years from its inception, and we're glad to see a lot of what's been changed this time around.

The following comments explain why OANHSS members believe that the amendments represent significant improvements over the original legislation. First of all, we'll speak to the Substitute Decisions Act.

By repealing the posting of security for statutory guardianship and making it easier for families to remain as powers of attorney, rather than referral to the public guardian and trustee, the new legislation recognizes the important role of family members in caring for their loved ones. This is something our members have experienced for many, many years, that the vast majority of family members do care about the seniors for whom they're responsible and who have given them that responsibility.

The removal of the validation process for powers of attorney: Regulations to standardize and control the costs of capacity assessments will ensure that the process is less bureaucratic and more timely than would otherwise have been the case. In saying this, however, we hope that the government will retain responsibility for the management of capacity assessment, including the recruitment, supervision and training of the assessors. This function especially should be assigned to a ministry with experience in and an understanding of capacity assessment.

In the area of the Health Care Consent Act, by introducing the simplified consent process, removing the rigid rights advice process and eliminating the requirement for a family statement, the proposed amendments create a much more user-friendly and effective process for consumers and providers, and we think this is extremely important.

By expanding the definition of "treatment," including plan of treatment and including the withholding and withdrawal of treatment, the government clarifies its intent and ensures that interpretation across service disciplines and care facilities is consistent.

The acknowledgement that minor variations to the same basic treatment are acceptable and the continuation of treatment from one setting to another will ensure the provision of care in a more timely fashion. This is especially important for the elderly, who often move from a long-term-care facility to a hospital setting where their care is continued.

The enhanced role of the Consent and Capacity Review Board to deal with substitute decision-makers who are not acting in the best interests of the incapable person in giving or refusing consent-to-treatment decisions provides added protection to incapable individuals.

Other changes, such as expanding the list of substitute decision-makers, removing the seven-day wait for appeals, expanding the application of the hierarchy of substitute decision-makers to make more than treatment decisions, and expanding the liability protection of the health professional render the legislation much more workable for practitioners, consumers, families and caregivers.

We do, however, have some concerns and some suggestions on how the legislation can be further improved. As with any complex legislation, there are areas of concern, and the following comments and recommendations clarify our concerns and suggest modifications in the general approach or wording of the legislation.

Section 16, which amends subsection 27(3) and (3.1). OANHSS supports the inclusion of these clauses, but we are concerned that there is no threshold increase for the investigation and action on allegations of financial abuse of residents by substitute decision-makers for property decisions.

When families refuse to pay for such things as hair-dressing, clothing, outings etc, residents' quality of life is compromised, even though the substitute decision-maker has control over residents' assets or have had assets legally transferred to them. Basic care continues to be met by the facilities. It's the extras that the residents don't get, and we think this is extremely important. We're not in the business of simply providing health care to our residents. We're in the business of providing a quality of life for them.

OANHSS recommends in this situation that a statement that the public guardian and trustee should investigate allegations of financial abuse by substitute decision-makers be included in the legislation.

Section 58, which amends subsection 87(1). The proposed amendment is unclear about the type of advice and assistance expected of volunteers. Volunteers would require appropriate expertise and extensive training in order to accept assignments and provide advice.

Our recommendation around this area is that the legislation include a provision that clarifies the role of volunteers in the advice and assistance process and requires the public guardian and trustee to establish volunteer recruitment and selection criteria, to develop a recruitment process and provide suitable position descriptions, training and supervision of volunteers so we can have the volunteers well trained in doing the right things.

Subsection 60(3), which amends subclause 90(3)(e.4) (ii). OANHSS is unsure of the rationale for this section and we're concerned that the proposed amendment may result in the application to become a guardian for personal care and property simply in order to access confidential client records for other purposes.

The OANHSS recommendation around this is that the government eliminate subclause 90(3)(e.4)(ii) or establish mechanisms to ensure that confidential and personal records are used only for the purpose intended in the legislation.

Mr Klejman will now comment on recommendations in the Health Care Consent Act.

1140

**Mr Michael Klejman:** I'll begin with part I, general section. Subsection 2(1) provides definitions. We are pleased to see that the definition of "evaluator" allows for categories of persons other than health practitioners to be prescribed in the regulations. Other non-health professionals, such as social workers, are often involved with clients and could be the best persons to evaluate capacity for the purpose of admission and consent decisions. However, this may be a new skill for them and some other health professionals.



We're recommending, therefore, that the regulation do indeed allow persons who are not health professionals to be evaluators in addition to health practitioners. Also, with the introduction of the term "evaluator" should come a regulation to ensure that evaluators meet the qualifications required of capacity assessors under the current legislation.

Furthermore, the terms "personal assistance services" and "personal assistance plan" are new. As such, they create confusion. No one is really sure what they mean. The term such as "activities of daily living" has been widely used for over a decade and in fact is referred in the regulations to the Consent to Treatment Act, subsection 3(1). The recommended phrasing of the definition reflects the clause in the CTA as well.

We recommend that the terms "personal assistance services" and "personal assistance plan" be deleted and replaced with "activities of daily living" and "activities of daily living plan" in the definitions and in part IV of the act. We suggest the following definitions:

"Activities of daily living' means an activity that the person performs routinely and may include activities such as hygiene, dressing, ambulation, washing, grooming, elimination and positioning or other routine activity of daily living."

"Activity of daily living plan' means a plan that sets out one or more activities of daily living to be provided to a person."

Exclusion (f) in the definition of treatment would then read, "Assistance with an activity of daily living."

Part II of the bill, treatment. Often, especially with the elderly in long-term-care facilities, quality of life is an essential objective. Substitute decision-makers should be taking this into consideration when making decisions. As well, the "best interests" provision does not include a decision not to treat or the impact on the quality of life should a treatment proceed. The current language implies that treatment should be given. While the definition of "treatment" has been expanded to include the withdrawal of treatment, the concept has not been continued to the "best interests" test.

We recommend that the proposed legislation be amended to provide the balance between treatment and non-treatment decisions, to recognize quality of life as an element in determining best interests.

Subsection 23(1). The proposed legislation does not explicitly include mental suffering or risk of mental suffering in the meaning of "emergency." Our members are concerned that people experiencing such suffering could also sustain serious bodily injury if treatment is not administered promptly. Therefore, we recommend that subsection 23(1) be amended to recognize severe mental suffering or risk, as well as physical suffering.

Margaret will continue with other sections of the bill.

**Ms Margaret Ringland:** In part III, the admission section, we're quite pleased to welcome the separation of consent to long-term-care admission and consent to treatment. The issue of tying treatment to admission, as was the case in the Consent to Treatment Act, has been extremely problematic, as many of our residents do not have ongoing treatment needs. Having said this, though, OANHSS has one comment and one recommendation.

OANHSS is concerned that consent to admission to a long-term-care facility is still tied to health care consent decisions. Admission decisions are often made by residents in our facilities for reasons other than the provision of health care or treatment.

OANHSS therefore recommends the addition of a sunset clause to recognize this anomaly and allow for changes in the Homes for the Aged and Rest Homes Act, the Charitable Institutions Act and the Nursing Homes Act and any other legislation that applies to care facilities to deal more appropriately with the admissions issue.

Part IV, in the personal assistance plan area: In keeping with the revisions suggested earlier to the definitions, this part of the act should be renamed activities of daily living. While the concept of the plan will be incorporated in our recommendations that follow, we believe this section should relate to the activities, not just the plan. Many of our residents are capable of deciding about specific personal activities, such as whether they want to go to the bathroom, when they want to eat. However, the same residents may not be capable of making decisions about their complete plan of care.

The capacity test for a specific activity decision is indeed much lower than the case for treatment or care plan decisions. In homes for the aged, staff make every effort to encourage residents to retain as much individual decision-making as possible and to have control over their care and environment.

The proposed legislation, by focusing on the plan, which requires a higher degree of capacity, could result in substitute decision-makers taking over these minimal decisions on daily activity from the resident. In saying this, we still support having the legislation provide for those few residents who cannot make even these very low-capacity decisions or communicate them by an effective means—for example, residents in a stupor or in end-stage Alzheimer's.

In order to access substitute decision-makers without resorting to the public guardian, as is the case now for those who do not have powers of attorney for personal care, application of the hierarchy to obtain substitute consent is much more practical.

In the context of these overall comments, the following additional recommendations are made:

Part IV of the legislation provides a framework for activities of daily living decisions only in care facilities; however, the location in which care is delivered should not be the determining factor in setting the rules. Should not those in communities and hospitals have the same safeguards?

OANHSS recommends that part IV be reviewed to ensure that it does not inadvertently create a situation where the only means to obtain the necessary consent for care to an incapable person is to place them in a facility as defined by this act and its regulations.

As activities of daily living are listed as an exclusion from treatment under the definition section, it is important to recognize they are still subject to the principles of common law.

Therefore, OANHSS recommends the addition of a clause to state that this does not affect anything related to the giving or refusing of consent not included in the definition of activity of daily living in subsection 2(1).



Sections 55 and 56: The language as it's currently drafted needs revision to reflect the use of the new activities of daily living terminology.

OANHSS recommends the following: If a person is incapable with respect to assistance with an activity of daily living, consent may be given or refused on his or her behalf by a person in one of the following paragraphs, and we would then list the same list as is in section 18.

It is a fact that there are times when it may be impossible to obtain a substitute consent in some circumstances. In these cases, it is necessary to have a provision that ensures that we can continue basic personal care, such as toileting.

OANHSS recommends the addition of a clause as follows: "Despite any law to the contrary, if a person is found by a health practitioner to be incapable with respect to an activity of daily living, assistance with the activity of daily living may be given without consent if the health care practitioner has made reasonable effort in the circumstances but has been unable to obtain consent to or refusal of assistance with activities of daily living."

The Homes for the Aged and Rest Homes Act, the Charitable Institutions Act and the Nursing Homes Act, as well as the long-term-care facility program standards, have specific requirements regarding the use of restraints that exceed the requirements in subsection 57(4).

OANHSS recommends, therefore, that the section related to confinement, monitoring and restraints be removed.

1150

OANHSS members believe that as with the Consent to Treatment Act, the new Health Care Consent Act does not remove legislative barriers to timely care for patients suffering from mental illness. The fact that mental illness is not treated in the same fashion as physical illness stigmatizes again residents in our facilities who suffer from some form of mental illness.

Finally, regarding the regulations, we hope that the regulations previously drafted under the old restrictive legislation will be revised too, in keeping with the changes introduced in Bill 19, and we would ask that our association be consulted during the regulatory drafting process.

I turn it back to Carol.

**Ms Shaw:** That's our submission, ladies and gentlemen. We support, as OANHSS, the government's intent to move quickly to amend the consent and substitute decisions legislation and to repeal the Advocacy Act. Bill 19 contains the major principles that should be included in a consent law but requires some revision to ensure that there is clear legislative authority for substitute decision-making for all health care—that is, with respect to treatment, activities of daily living or admission to care facilities.

We hope this information will assist the committee in its deliberations and provide suggestions that can be incorporated into the final legislation. As previously stated, our submission will be in your hands hopefully later on today.

**Mrs Boyd:** Thank you very much for your presentation. You make a lot of very good suggestions and I thank you for them.

I have a couple of questions. One of the things that worries me is that we see consumers of health care services consistently coming in front of us and regretting the cancellation of the Advocacy Act and we consistently see providers coming in front of us and saying, "Good for you for repealing the act." That makes me uncomfortable. Are you saying that you don't think there's a requirement for rights advice to people who have been declared incapable, and you think this act is okay when it doesn't give people the information that they've been found incapable?

**Ms Shaw:** Michael, would you like to comment? I think we all have a fairly strong feeling about this issue.

**Mr Klejman:** You may not be aware of it, but I am one of the 12 commissioners—

**Mrs Boyd:** I'm very well aware of it.

**Mr Klejman:** —on the Advocacy Commission who has not been able to fulfil my role, and I'll be back here, I believe, on Wednesday.

No, we do not say in our brief that we are against advocacy, the need for advocacy. We are willing and are involved in discussions and consultations about alternatives to the model that was proposed through the Advocacy Act. So I think maybe we were remiss in not referencing that in our submission, but we do believe there is a role for advocacy and we believe very strongly that our members have been in the forefront of providing advocacy not just on behalf of the individuals but also their families and working with their families.

**Mrs Boyd:** There are a few other issues I'd be interested in hearing your comments on. First, do you think paid caregivers ought to be able to be substitute decision-makers; and second, were do nutrition and hydration fit into treatment versus activities of daily living, and where do we locate consent to nutrition or lack of consent to nutrition and hydration?

**Ms Ringland:** I think there are two types of treatment and activities of daily living. In the issue of nutrition, feeding someone, providing food, helping them to eat would be an activity of daily living. What they eat and special nutritional assessment and special nutritional needs would be in fact treatment decisions. So I think it's quite clear to providers which is which, and the same would be the case, I think you said, with hydration. Again, helping someone to take some fluid, to check on their fluid and make sure they get it and they can receive assistance with that are activities of daily living, but in fact, special requirements that they may need in order to enhance their hydration because they're not drinking properly would be treatment decisions.

**Mrs Johns:** I was just interested in your part IV discussions talking about the location and how you thought the definition maybe should be broadened. I guess the concern is, how do you broaden that and make controls and allow the process to move forward? Since we haven't seen your brief, I don't know specifically how you're amending it. Can you just talk a little bit about how you'd like to see the groups broadened?

**Ms Ringland:** I would think the way the act reads now it applies only to the facilities and to other care facilities defined by the regulations. I think our concern would be that in fact if you're in the community or you're in



whatever location that isn't defined by the regulations, there wouldn't be access or there wouldn't be consideration given to your right to make decisions around your activities of daily living. We think there's no need for this section to be confining to facilities, that it could be opened up to wherever a person is provided services by health care professionals.

**Mr Klees:** Perhaps I can just follow up on that. There has been a suggestion made in the past that perhaps rather than defining it as health care facilities that it be termed, I think, a treatment plan; rather than treatment facility, a treatment plan. Would you be comfortable with something like that, and that would then apply to whatever facilities you're in as long as there has been a treatment plan defined?

**Mr O'Krafka:** Our understanding is, the legislation, as amended, picks up and allows for that and actually that was one of the things we were complimenting government on, was the continuity of that treatment plan and care plan.

**Mr Klees:** Okay. One other follow-up, perhaps. One of your members has had some experience with the commission itself. Could you just give us a couple of comments as to what you feel the effectiveness of the commission was and why you feel that should be changed.

**Mr Klejman:** I think the commission became very focused on certain types of activities and, frankly, it controlled under individuals with, first of all, vested interests representing their own interest groups and, secondly, not willing to look at the broader spectrum of the population and the service provider side and work in some sort of a collaborative way. It simply froze some members of the commission out of the decision-making process within the commission.

**Mrs Caplan:** Thank you very much. I would like to discuss with you and have your views on the differences between evaluators and assessors, and also from that aspect, you've rightly said that evaluators will be able to be defined by regulation, so they will not only necessarily be professionals as defined under the health professions legislation. Therefore, the concern that I have and I've expressed on numerous occasions is that the act must have an obligation to oblige evaluators, as it does assessors, to inform patients when they are not able to make decisions for themselves and also to inform them of their right to appeal. That is something that is an obligation of assessors who are assessing for the purpose of guardianship, but evaluators who are doing, I would say, a very different and more minor capacity assessment for the purpose of a one-time treatment or a series of treatments, as contemplated by the legislation, have no obligation. We've heard that several of the colleges, including the chiropractic college, are saying don't do it under the regulated health professions legislation.

Do you believe there should be an obligation in this statute that states clearly the obligation to inform someone who's been found unable to understand and appreciate the consequences and also inform them of their right to appeal? Should that be in this statute or is the RHPA a better place?

**Mr O'Krafka:** We're quite comfortable with it being in the statute and our recommendation around that was

specifically that the evaluators have the same training that capacity assessors have, so that we're—

**Mrs Caplan:** That was my next question.

**Mr O'Krafka:**—dealing with people who understand what they're dealing with.

**Mrs Caplan:** My concern, frankly, is that there are very few capacity assessors that are certified and I think it's unrealistic initially to have in the legislation that same category. There's also no requirement at this time for any training for evaluators; there is for capacity assessors from the capacity assessment office and I support that. I do think that the education that professionals receive who use their skills all the time to assess the ability of their patient to comprehend and appreciate treatments could be different than someone who is assessing for the purpose of long-term guardianship.

I support the differential between the two. I also think practically it would be impossible to make that a requirement of the legislation at this time. It might be a goal that you'd want to aspire to, but I'm not certain you would have enough time to have everybody made a capacity assessor. Do you have anything you want to say on that?

**The Chair:** Thank you, Mrs Caplan. I always do it to you.

I would like to thank you very much for your detailed and thoughtful presentation. I'm sure the committee appreciates it, along with myself. Thank you.

**Ms Shaw:** Thank you, Mr Chairman.

**The Chair:** I had two matters to raise, if I could, at this moment: Next week is clause-by-clause and I am suggesting—and think it over during the lunch hour; if there are any objections to this procedure let me know or raise it—that amendments should be in no later than this Thursday from all the caucuses.

Secondly, on the clause-by-clause, I suggest it may be unsuitable to do a clause-by-clause in room 151, being the Amethyst Room and televised, and I am therefore—

**Mrs Caplan:** That was okay for Bill 26.

**The Chair:** Well, I'm suggesting that we move it to a non-televised room for next week. Again, if you have any objections let me know.

The 1 o'clock appointment has been cancelled. We are recessed to 1:30 this afternoon. Thank you.

**Mr Parker:** Mr Chairman, before we break just one other point: Last week, Mrs Boyd asked for data on treatment decisions in the office of the public trustee and I have that information with me here that I'd like to table with the Chair. This covers the period from April 1995 through December 1995.

**The Chair:** Thank you very much, Mr Parker.

*The committee recessed from 1202 to 1332.*

## RIGHT TO LIFE ASSOCIATION

**The Chair:** Good afternoon, members, ladies and gentlemen. If we can proceed, our first submission is from the Right to Life Association. Dr Barry, would you identify the people who will be making the presentation with you for the purpose of Hansard.

**Dr Michael Barry:** This is Mrs June Scandiffio, president of Right to Life Toronto. I'm president of Right to Life Mississauga. This is Mrs Gwen Landolt, the legal representative for Right to Life Toronto.



**Mrs June Scandiffio:** If I may, I'd like to introduce our committee. We have been looking at the history of this legislation and following it closely since 1991, when we presented a brief, and then again in 1992. Generally speaking, we are very pleased with a lot of the changes and streamlining, in particular the fact that families have been given more of a voice and a say. However, we do have some concerns of what we see as possible inconsistencies and our brief outlines them. On page 3, we have an executive summary and then there are more detailed positions within the paper.

We have two basic concerns, I suppose, one dealing with minors and the other dealing with either the incapacitated or the elderly patient.

Under the Consent to Treatment Act, there's no minimum age given for the person making their decision. Further, there's no provision for parents even being notified that a minor is seeking medical provision.

We have a number of concerns here. First of all, how well informed can informed consent be where we have, by the young person's very nature, perhaps the inability to understand the repercussions and the risks? Second is the fact that most people of course presume "health care practitioner" means a medical doctor, but not necessarily, as we know from the definitions within legislation.

If a young person appears before a health care professional and is under 16, perhaps there would be undue weight given to the opinion of that one particular person, and in fact perhaps then a conflict of interest, because the health care professional, if a parent is not notified or consulted, may in fact be the only adult making any input.

We see a real inconsistency in the rest of the legislation; for instance, the legislation for a substitute decision-maker. A person must be at least 16 years old to be designated as a person who is capable of making substitute decisions for someone when they become incapable, and yet there's no provision within the Consent to Treatment Act itself for that age. It appears in a number of areas and we've listed them in our brief. Certainly there's also a problem and a possibility of the whole legislation being unconstitutional, and that will be dealt with a little later by Mrs Landolt.

In terms of the consent to treatment, we're very concerned that, as far as we can see in our reading of the legislation, when a person is found incapable, they are not notified of the fact that they've been found incapable. To me, this is a very serious flaw. If in fact a doctor or a health care practitioner has found an individual incapable, at a minimum they should be notified that they have been found incapable and that there's a mechanism with the appeal. I think that's a real flaw that has to be addressed.

In addition, if in fact the person is found incapable and they themselves cannot understand this whole thing, there should be a family member who is listed there as well.

Under the "best interests" doctrine, and I'm just going very quickly through some of our major points, we've been concerned especially for the vulnerable who are on assisted nutrition and hydration. As you know, the ongoing concerns in Canada on euthanasia and assisted suicide have really been at the forefront. I know that the proposals made by this government do not have as the intention to bring in euthanasia through the back door,

but in fact in other legislation in the world nutrition and hydration when assisted, or sometimes called artificial nutrition and hydration, can be denied. In fact, we have numerous cases in the United States in particular where the person has not died of their underlying illness but the fact that they were not given proper nutrition and hydration.

I would ask you to take a look on page 9, where there are a number of medical ethicists. Daniel Callahan is not pro-life by any stretch of the imagination, but given our economic concerns all across our country, budget restraints and so on, this isn't just an academic question, and I quote him:

"A denial of nutrition may in the long run become the only effective way to make certain that a large number of biologically tenacious patients actually die. Given the increasingly large pool of superannuated, chronically ill, physically marginal elderly, it could well become the non-treatment of choice."

We're delighted that you have moved nutrition and hydration from treatment to care, but in fact under the Substitute Decisions Act the substitute decision-maker can in fact still decide what care, and that's fine, but I think we have to make it eminently clear that nutrition and hydration should be basics of life. Whether you are an Olympic star or a person with multiple handicaps, in both scenarios people would die if they were not given nutrition and hydration. We have to be sure that we are not discriminating, particularly against those who cannot speak for themselves.

**1340**

If in fact we have a person who is capable, who does not want to have any more food and water given, that's one scenario. But we're talking about the incapacitated, and I think it has to be very clear; or those who are seen perhaps as better off dead or because they're an economic burden. All we have to do is look demographically. The problem is tough now; it's going to get worse in 2010. I'm sure I don't have to bring in the demographic studies, but if anyone is interested, we have all kinds to show that demographers across the country are increasingly concerned that we have a large number of people currently but there are going to be fewer young people able to work and pay taxes and a growing number of elderly. The problem is going to get worse. I think we have to make very sure that in fact we are looking after these people.

Getting back to the consent to treatment for the young, and then I will hand over to my colleagues for some of their comments as far as their professional expertise is concerned, on page 5 we've quoted Dr Carol Cowell, who again is not pro-life; she favours the option for abortion. In the 1970s, when she was working at the Hospital for Sick Children, she said:

"I would caution physicians against accepting carte blanche the 'self-consent' of an adolescent girl 16 to 17 years of age for this abortion procedure....I continue to be astounded at the lack of knowledge of this group as to what is involved in a therapeutic abortion and its inherent risks...."

"Paradoxically, when the age of minority was 18 years, there were fewer problems than when it was reduced to



16 years. The depth of understanding and knowledge of the average 16-year-old is best described as 'impoverished' when compared to that of an 18-year-old....At the time of an abortion, the younger teenager needs more than ever the support of her parent (or parents) because abortion is a very lonely experience."

I can tell you from my own experience. I'm a high school English teacher by profession and I know that our young people are very bright and very articulate, but nothing of course has more of an impact than their experience, and the older they get, the more they understand implications and problems.

You will notice in our recommendations that even though Dr Cowell has 18 years, we are saying at the minimum it should be at least 16 years. Because if Dr Cowell found that 16-year-olds' ideas and information as far as risk is concerned were impoverished, things haven't changed that dramatically, I can tell you from my experience with young people.

The heartbreak that I find when I go out to speak at universities or community colleges, especially to adult or young adult groups, is that almost inevitably I'm followed into the parking lot by a young woman who perhaps had an abortion when she was 15 or 16 or 17. Very frequently they will say to me, "I had no idea. I hadn't taken any biology. I didn't know it was going to have the emotional impact," and so on. Now obviously not 100% of women are going to experience this, but I think we have to think very carefully of having some kind of age limit there.

I'll hand things over to Dr Barry.

**Dr Barry:** As Mrs Scandiffio said, there's much to be commended in Bill 19. There seems to be some concerted effort to restore the confidence in the professionalism and integrity of the treating physician—I speak specifically being a psychiatrist—and to restore the family and the close relatives as the most appropriate advocates for the sick. This I see as positive within the bill.

My problem, as Mrs Scandiffio has mentioned, is the definition of "minor" in respect to treatment. The act in fact refers to the age of 16 as the legal age of maturity in subsection 18(2) and in other sections, and I would trust that the absence of an age of maturity in the consent to treatment section is an oversight on the part of the formulators of the document. I would hope so.

We are all aware that the use of birthday as a measure of intellectual maturity has definite limitations. In the case of the definition of judgemental maturity in a minor, it is the best we have. No one objects to the age prohibitions based on sale of alcohol, cigarettes and minimum age for driving. It is a much more onerous responsibility to make a decision about one's own treatment. Even adults, from my experience, seldom make treatment decisions without conferring with other family members. My experience in psychiatry has taught me that making decisions in a vacuum, that is without as much family involvement as possible, often results in diagnostic error and undue harm to the social structure and harmony of the family.

This is especially true when treating an adolescent or young adult. Minors, in their struggle for autonomy, will often make a decision counter to their parents' wishes,

willing to take the consequences after the fact, and these consequences are often disastrous.

Whereas in the last decade, a parent's rights and authority over the minor have been increasingly usurped by government, this bill could restore at least some of those rights and responsibilities, which the family have never lost. Governments for that matter and professionals, in an effort to be non-judgemental, make decisions devoid of any moral underpinnings, and it is up to the family to add the moral dimension to all decisions in the case of minors, and no one else.

That's all I have to say.

**Mrs Gwen Landolt:** Hello. I'd like to raise two comments as a lawyer. I'd like to bring to your attention a very important Supreme Court of Canada decision that was passed just a year ago. It's *R(B) v Children's Aid Society et al*, and in that case, the Supreme Court of Canada held that it is a fundamental aspect of freedom of religion, guaranteed by section 2(a) of the Charter of Rights, that parents must be notified and have knowledge and must be involved with the children's medical care. Mr Justice La Forest said:

"Although [in Canada, a parent's] liberty interest is not a parental right tantamount to a right of property in children, our society is far from having repudiated the privileged role parents exercise in the upbringing of their children. This role translates into a protected sphere of parental decision-making which is rooted in the presumption that parents should make important decisions affecting their children because parents are more likely to appreciate the best interests of their children and because the state is ill equipped to make such decisions itself."

Mr Justice La Forest goes on to say:

"I would have thought it plain that the right to nurture a child, to care for its development, and to make decisions for it in fundamental matters such as medical care, are part of the liberty interest of a parent," under the Charter of Rights.

In effect what they are saying is that if proceeding with Bill 19 as it is, it will inevitably be subject to legal challenge because of this recent decision of the Supreme Court of Canada saying that parents do have a fundamental right under section 2(a) of the Charter of Rights to have involvement in the medical care of their children.

It's amazing to me that this bill managed to be drafted without this being taken into consideration. It appears to be an oversight that they have neglected to do their research legally on this very important aspect of the situation.

The second thing I want to bring to your attention is the question of capacity of a vulnerable person. Under this particular legislation, I note that there is no criteria set out as to how a medical practitioner would determine the capacity of a patient. Under the previous Substitute Decisions Act, there was a criteria. For whatever reason, it was dropped in the present Bill 19, so that a medical practitioner would simply determine, on his or her own, whether that person has a capacity, and if they decide the person doesn't have a capacity, the only appeal is to a consent review board,

What puzzles me is that this legislation appears to have dropped out a whole section as to how does a person



who's been deemed to be incapacitated know what to do, who's going to advise them. There seems to be a whole section removed. There's no protection for the vulnerable person and, significantly, there is no provision that the person's family would have, as a right, the power to go to a board of review. In other words, you've got a physician who may or may not have his or her own particular bias declaring that person lacks capacity. The only avenue of appeal is to go to a board. The only people who have a right to go to the board is the person who's incapacitated, and there's no provision to let him know that he has this right.

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The second thing is the physician himself; there's no place for the parent. There's no criteria. In other words, you get enormous unfettered power into the medical practitioner to make this absolutely earthshaking decision. There is a whole section missing to protect that person, because that person has no one to tell him that he has an avenue of appeal, and there's no provision for his family or anyone else to stand in and to protect him to let them know if it goes to the board, and there's no provision for his family with regard to the board.

Somehow, something has happened between the substitute consent act and this particular piece of legislation. Something was dropped out. Hopefully, it was inadvertent. But we have in effect that vulnerable person simply left high and dry once they're declared to be incapacitated.

Thanks very much.

**Mrs Scandiffio:** I'd like to end our formal part before the questions with just reiterating what our recommendations are; they are found on page 10 of our brief:

(1) The age of consent for minors be set at 16 years of age.

(2) That persons deemed incapable be notified of such findings and their right to appeal to the Consent and Capacity Board.

(3) The "best interests" of an incapable person should be based on a presumption in support of treatment. Provisions should be made for application to the Consent and Capacity Board if cessation of treatment is desired. Right now the reverse is true.

(4) Conscience clause, which I have not touched on—under the liability from protection there is quite an onerous fine levied, and as with the abortion law, we think that health care practitioners and substitute decision-makers should be able, without penalty, to refuse to implement instructions that will cause the death of a patient when such contravenes their conscience. There simply should be some form of conscience clause within the legislation.

We know that all of the people who have been presenting to this committee have the best interests of the citizens of Ontario at heart, and I've been very impressed with the research that's gone into the presentations at this committee. I know you're here to protect all people in Ontario, but I hope you will give special attention to the most vulnerable, the very young and the very old.

**Mr Klees:** Thank you very much for your presentation. I'd like to just take a minute to pursue your first recom-

mendation with you, with regard to the age of consent for minors to be set at 16.

As you know, there is no such age now, and there are those who would say that if you insert that age of 16 many young people who find themselves in a situation of having to consult a doctor because they feel they may be pregnant or may have a venereal disease, choose not to if in fact their parents were to be brought in. In addition to that, there are young people today in society who don't have parents to turn to. They are homeless and so on.

Having said that, I don't disagree with you personally, but we need some help with this. How do you address that?

**Mrs Scandiffio:** Certainly in terms of the young people who are street people, who don't have a home or an adult that is there responsible for them, I think we have provisions now under the child health care act, but more importantly perhaps we should make provision for unemancipated and emancipated minors. In other words, make a distinction.

According to a survey done in 1993, 86% of our adolescents live in fact with an adult who for the most part we presume has their best interests at heart. Obviously, not all parents are going to be the best of parents, and we have provisions for that under the Child Welfare Act and so on with children's aid.

But the idea of making legislation for that 14% of the population where we could protect them as well by having different classifications—in other words, that I as a parent am responsible for my children who are living at home under a certain age. And to put just the responsibility on the parent and not have any of the—we presume that there's an adversarial role here with the parent and child, and from my own experience, we've all heard kids say, "My parents will kill me." As an English teacher, if a student has failed a test and I say, "I think I'm going to have to call your parents," they're not going to be very pleased about it. I'm not doing it to get the kid into trouble, and if I felt in fact that the student really was going to be physically abused, I would do something else. But the fact remains that most parents have the best interests of their children at heart, and we want to work in concert. It's not a matter of parents against kids, but in fact that the family should be a unit.

The loneliness of a girl who is faced with this situation is palpable. I've been on the phone with girls who are calling me, who are pregnant and they don't know what to do. The parents pick up the extension saying: "Will you get off the phone? You're always on the phone," and I'm thinking if these parents even knew what this conversation was about. It's very, very difficult for this young person to make this decision, and I don't think it's fair for them to have to make it alone.

I encourage dialogue and will go with them, if they want, to talk with their parents, to say that you need people at this point. Parents are going to be disappointed, but they're not going to hate their kids. In fact, they will feel that they have failed as a parent rather than blaming the kid. That's been my experience.

**Mrs Landolt:** I'd like to mention too, if I may, that the way to get around that problem is to put in the legislation that there would be a presumption of incapac-

ity under 16, but that is always a rebuttable presumption, and there may be extraordinary circumstances that may denigrate from that and change the capacity. But if you put in "the presumption of incapacity under 16," it can be rebutted in extraordinary circumstances, as a way to get around that problem.

I just don't think that a physician, who doesn't even know the child, and the child doesn't even know its own medical background, should arbitrarily decide that, "Oh, yes, they have the capacity and, therefore, in my view, they should get this or that," and the parent, who has known the child since the moment of birth, is totally cut out of it.

The other problem is—

**The Chair:** Thank you. Sorry. Excuse me, we have to move on to the next caucus because of the time constraints. I'm very sorry for interrupting you.

**Mr Ramsay:** I'll probably give you an opportunity to continue, because this is the area I'd like to talk about too, the age of consent.

I'll tell you, as a legislator, it's difficult at times, as Mr Klees said, balancing one's own views, the various beliefs we hear when you're on committee, what our perception is and maybe also what's realistic out there. It's difficult for us. I'm not sure we should have an age limit set.

I speak as a father of two daughters who are now young women, and also a person who believes that children grow up too fast, but I know in the best of families and in the worst of families, there are some things that sometimes don't get communicated that should be. I wish they were, and in an ideal world, they would be.

I'd hate, as a legislator, to put something in legislation that might prevent a young person from seeking the medical help they possibly need because of the embarrassment of the eventual confrontation of whatever is happening with that child with the parents.

So it's difficult. My heart goes out to you. I understand where you're coming from, but I guess our job here is to try to find some balance.

**Mrs Scandiffio:** If I may comment on that, to me the heartbreaking thing with a lot of these teenagers, and I find it kind of mind-boggling as a parent myself, is that the young women who find themselves pregnant aren't so much afraid to tell their parents that they're pregnant; the bottom line is they say "Well, then they will know that I have been sexually active." It sounds ridiculous, but that's kind of the way they're thinking, that "I'm going to disappoint mommy and daddy."

The pregnancy is kind of a symptom of the other problems, as it were, and my concern is the making the decision, as Dr Cowell herself said, that the long-term implications, I find for the young women in particular—I noticed in the Toronto studies of health that for young women, a lot of times the father of the baby or their partner is a lot older. That makes it even worse. To me, these young girls that—and I'm speaking from my own experience of the young women who are calling us or coming to visit us—there's no one to advocate for them. If the girl is 15 and going out with a boy who's 19 or 20, this is not an equal relationship, and often the father will be pushing for the abortion because he doesn't want to

take any responsibility, and he's scared too. I can't fault him. But to say that this 14-year-old is not being either pressured or coerced, especially if she doesn't have any adult who knows her to even say what the options could be for her, to me is not liberating these young women but in fact victimizing them. That's heartbreaking to me, because often the partner will be the one who's pressuring. All studies will show that the partner in any pregnancy has the most say as to the outcome of the pregnancy.

**1400**

**Mrs Boyd:** Thank you very much for the presentation. I share your concern around nutrition and hydration. I'm not sure your solution is a solution that meets the need, but I want you to know that I'm quite concerned about that. I think it is a loophole in this and I'm curious to know whether you think putting nutrition and hydration in some special category might solve the problems. It is a very difficult issue.

**Mrs Scandiffio:** Certainly if the person is imminently dying and their body can no longer absorb and utilize, obviously we are not there to prolong the dying or the suffering. That is not our concern.

**Mrs Boyd:** But we know it happens in other circumstances where someone is just taking too long and people get impatient, don't we?

**Mrs Scandiffio:** That's right, or people who are in a persistent vegetative state where, especially again with health care costs, these people can live for a long time; they're not on any extraordinary respirators or anything else; they're just simply being given food, often with the nasogastric tube to save money, not because they couldn't swallow initially. It becomes a real problem.

**Mrs Boyd:** On your situation around children, I would suggest to you that the case you cite, where the child was quite young and it was a case where the children's aid society had taken the child and had made different decisions than the parents, leads us right back to the same old issue. Your solution to the problem around dysfunctional families and where children couldn't get support was to give them to the children's aid society. The case you cite is exactly the reason why none of the parties here believe that's the solution to the case, because we can't protect that child under those circumstances.

It is a real conundrum. While all of us would want you to know how much we respect the concerns you're raising, the problem is that in looking at this over many years, the issue of presumption of consent for children and young adults has been one of the things we generally have agreed on among the parties here because of the problems of coming up with any other solution.

**Mrs Scandiffio:** I guess the concern, and I appreciate that you can see where we're coming from, is that for a lot of these young people, certainly when you look at different jurisdictions where they've legislated age of consent for particular procedures, certainly in terms of illegitimate births and abortions, both have gone down when parental consent was required. These are long-term studies.

I don't want to make this an adversarial thing between the parents and the child; I don't think that's the role at all. But what happens with a lot of these young women is that the parents are there to pick up the pieces after the



fact. Eventually they find out about the abortion—it may be a long time down the road—and to me, it just doesn't make any sense that we don't have some kind of way to help these young people understand that the bottom line is that their parents love them. There are going to be some exceptions, but we can't make laws for the exceptions.

**The Chair:** Thank you very much for your thoughtful presentation.

**Mrs Scandiffio:** If anyone is interested in any further background or research, please feel free to contact us. We'd be happy to provide it.

#### ONTARIO AIDS NETWORK KINGSTON AIDS PROJECT

**The Chair:** The next submission is the Kingston AIDS Project, Paul Waltenberry and Mark Bulbrook. Welcome.

**Mr Mark Bulbrook:** Good afternoon. My name is Mark Bulbrook. I'm the executive director of the Ontario AIDS Network and represent the Ontario AIDS Network this afternoon, along with Paul, who is representing particularly the Kingston AIDS Project.

The Ontario AIDS Network is the provincial umbrella organization representing 48 member agencies which are all AIDS service organizations providing education and support throughout the province to people living with HIV, affected by HIV, and most targeted to the risk of the spread of HIV.

As well as being the executive director of the Ontario AIDS Network, I'm also a person living with HIV, a person living with haemophilia and a person living with hepatitis C, and have a lifetime of experience around advocacy and consent to treatment and hospitalization and vulnerability and all those things.

I'm going to be somewhat brief. We're dealing with three specific areas of the act today, the first one being around consent to treatment. The Ontario AIDS Network firmly believes that the consent to treatment beyond the ability of the patient belongs to the partner of the patient, where a partner is involved, and this includes same-sex spouses as well.

To allow the decisions of treatment to be left with traditional family members when the patient may not have even disclosed their illness—that being HIV infection—or the fact that they're gay and their sexual orientation to their family members throughout their lives, to then expect those same family members to step into a situation and deal with consent to treatment for this person is not only unrealistic, it is wrong. It should be the privilege of certainly the partner of the patient, the person who knows the patient best and the person that this patient has been able to disclose both his sexual orientation and HIV status to.

I ask you to try a bit of an illustration on this, because it is an area that a lot of people have a difficult time comprehending, but if you can for just a few minutes imagine yourself as a gay man, that you are now in your mid-30s, that you have hidden your sexual orientation from your family, including your parents, all of your life because of the stigma and discrimination associated with homosexuality, and then on top of that you discover that

you're HIV-positive, and you have a partner. Imagine the trauma and the impact this would have on your life and then trying to disclose both of those double whammies, one of which means that you're in for a very long, chronic illness leading to death, and having to inform your parents and your family of all this information all at once.

When it comes to the consent to treatment, the person who has the right and the privilege of taking care of that person, without question in the mind of the Ontario AIDS Network, is that person's partner, and that person being a same-sex partner.

Around the capacity review board, the OAN strongly disagrees with the proposed amendments which see one person who may have a potential prejudice towards the patient due to sexual orientation or other as having the sole authority on judging the patient's ability or capacity to make his or her own decisions. We would support the continuance of a capacity review board of more than one individual to make that judgement of that person's capacity, and that review board would have the final say over the attending physician.

The third area is the provision of a rights adviser. The Ontario AIDS Network disagrees with a system where only the members of the medical community would inform the patient of their rights as opposed to having an outside adviser or advocate assisting the patient with these rights.

Again, imagine if you would that you're hospitalized for something. Once you are hospitalized, you're vulnerable. Everyone is, no matter what capacity they're hospitalized in, because you're at the mercy of an area of expertise which most lay people simply lack. It's the same analogy if I were to take my car into a garage to have something done to the engine. I know nothing about cars and my trust and faith must lie with that mechanic, his honesty, his integrity and his credibility. I would then not lay all my trust with that mechanic. I would get some outside advice, perhaps go to someone I know who is a mechanic, someone I can trust, someone who may not have a vested interest in the bill that work comes to.

The same thing applies to hospital care and medical care. We strongly urge that the rights adviser remain a part of the Advocacy Act, that people have an opportunity to seek advice on their rights and on proper medical care from an independent person as opposed to just their physician.

I'm going to stop there and pass it to Paul. I welcome your opinion on some of the things I've talked about as well.

1410

**Mr Paul Waltenberry:** First off, I'd like to take a moment to thank certain members of the Ontario Advocacy Commission who are here today and who work for them, and all the other people who were employed by the commission, for their work since 1992 and the passing of the Advocacy Act.

I'd like to stress that I'm really disappointed that the consultations into the repealing of the Advocacy Act are so small and they're in very distant areas. I had to drive three hours from Kingston to Toronto to appear before this committee.

There are several reasons why I submitted my name to present before this committee, and I'd like to take a few moments to comment on areas that are of grave concern to me and the community groups I represent.

Mark was saying earlier that he's representing people with HIV and AIDS and that community. What I'm doing is I'm speaking on behalf of everybody who is living with a disability, all the cross-disability groups that are represented. In Kingston, we serve a catchment area of approximately 100 miles, which includes eight counties. Five of those counties are rural communities. Many of the people who live in the rural communities are senior citizens and people with disabilities.

In Canada, there are approximately about 70,000 people living with HIV and AIDS, and 41% of that number live in Ontario. That represents a large number in Ontario. The mandate of AIDS service organizations in this province is to advocate and improve the quality of life for people living with HIV and AIDS.

For the past 100 years or more, vulnerable people and individuals from cross-disability groups have faced discrimination and abuse stemming from such things as financial abuse, sexual and emotional, neglect, intimidation and just plainly being pushed aside. In repealing this act, it will put advocacy back years and will allow for the same sort of abuse to continue, with no independent regulation, protection and rights for the various individuals who represent and make up the cross-disability groups of Ontario.

I will not even try to tear apart this act because I'm not a lawyer. It would take a team of lawyers to review this and even then it would be difficult to interpret. As you're looking at the act, and every member has a copy of the act, if you look at one paragraph in the act, it says, "Refer to subsections (4), (5), (6) and (7)," and every subsection you refer to refers you on to other subsections and other subsections and other subsections. So what you're doing is you have one paragraph, and after you read 15 subsections, you see the contradictions all the way through it.

I've shown it to normal, common people in Kingston and we can't make head or tail of it. So for this act to be repealed so fast and the amendments to be made to the other acts is just ludicrous. It's outright abuse of a system of power. It's outright abuse of a government pushing things through and putting the vulnerable people of this province at risk. That's what we're doing.

As Mark was saying, decisions on treatment that are left to traditional family members do not necessarily respect and reflect the best interests of the individual who is needing treatment. Years ago when I first started to advocate on behalf of the various cross-disability groups, the one commonality I found was that the traditional family member, as we'll call it, has been proven to be the main abuser in almost 90% of the cases where senior citizens are concerned. I have a report in my bag that I'll pass out afterwards; the only report I could find in three weeks of researching was done by Stats Canada. It showed that 90% of the cases of abuse happened by family members where seniors were concerned.

It is my recommendation that an independent party, as proposed by the Advocacy Commission, be established as

a non-profit agency made up of individuals who represent the various cross-disability groups. In my opinion, I do not believe that putting the consent to treatment back in the hands of the traditional family member and health care officials, and the government's decision to remove someone's access to rights advice, are sound and safe. There needs to be an independent, non-biased party who will make the patient aware of all avenues available to them. We had this party within the Advocacy Commission.

Therefore, my proposal to this committee and this present government is to leave well enough alone, and to reach beyond the scope of dollars and cents and protect the vulnerable of our society.

I have spent the past year working closely with the Advocacy Commission. Before I go on, when I first heard about the commission in early 1995, a regional representative came up to Kingston and contacted the various groups and met with them. I came to Toronto to meet with the commission, because I didn't like the commission. I thought it was a farce. I thought it was a group of individuals wanting to come into our area to take over the jobs we had, to misrepresent people, to set up an office and be another arm of the government. But I was wrong. After a year of the cross-disability groups in Kingston working with the commission—and they have spent a year coming to Kingston, meeting with the various groups, advising them of their rights, advising them of what the government is supposed to be doing for them, of what health care is supposed to be doing for them. After a year, I've got to the point where I agree with the commission. It's a service that's essential.

Rights advice is exactly what it is—it's rights. If I'm going into the hospital or Mark's in the hospital, I'm very intimidated by a doctor. For a doctor to tell me what I need is like, as Mark said, putting your car in a garage. Sure, put it in, because I don't know, but if there's somebody else I can go to who's separate but mandated by the government, I'll feel safe.

The commonality between groups and individuals is that finally they have someone who will look after their best interests, and now they live in fear of the Advocacy Act being repealed. I caution this committee and this government that repealing the act will force people to live in isolation, fear, neglect and abuse. Even for this committee to suggest that formal advocacy is meddlesome and dangerous suggests to me that this government refuses to wake up and see first hand the realities faced by our disabled consumers. Furthermore, to suggest that volunteers take care of the vulnerable is a further indication to me that this government refuses to see the truth, and it only reinforces my worst fears.

The very foundation of this province and the social safety net under which we at one time could be assured of being taken care of was founded on the backs of the less fortunate in this province.

I would like to reflect to this committee that regardless of this present government's mandate to abolish and change anything the previous government had done, your battle should not be with the various cross-disability groups and the vulnerable of our society but with the previous government. Allowing for the fact that they no



longer are in power, why assault the various cross-disability groups and set this province back 100 years? Your battle is not with the cross-disability groups of this province; your battle is with the previous government.

I have had the displeasure of watching friends and colleagues and patients who are HIV-positive being treated with a total lack of respect, being discriminated against for their sexual orientation and for the simple fact that they're HIV-positive. This brings into concern and only reinforces the position of an independent rights adviser for people.

I have worked in a nursing home where the elderly were neglected, and when they did attempt to speak out, they were put on medication and silenced. I suggest to this committee that you visit an Alzheimer's ward and see first hand the neglect of daily care that goes on. I encourage you to visit hospitals and institutions, both private and government-owned, to see first hand what actually goes on.

This government has not gotten enough consultation into the repealing of this act and has not reached the consumer groups it needs to. When I was first approached about presenting to this committee, I suggested that I bring a whole group of individuals with me. I was told they could submit a written brief and either fax it or mail it in. Well, surprise, some of the people I spoke to had visible cues to their disability; many didn't, but most had a difficult time comprehending this bill, the amendments and revisions of the various acts. Many of the seniors I spoke to in nursing homes could not write because of arthritis or because of lack of eyesight or other illnesses related to getting old. People living with HIV and AIDS were scared of coming forward because that would disclose their status and then they'd be faced with much more to deal with.

1420

This government needs to take back its responsibility and protect the vulnerable of our province. Many of the cases of abuse that happen in this province do not get reported. Why? Because unless there's hard evidence it is difficult to prove. In a report published by StatsCan in 1992 with regard to senior citizens—and I might add that only stats of violent crimes are recorded—on page 6 it states that elderly victims were victimized by immediate family members more than others.

I ask this committee to set the stage—and Mark took it right out of my brief and I didn't know he was going to say it—for an individual who's gay. They know they're HIV-positive, and they have a family that's really homophobic. They live in a rural community and now they need treatment. Who's going to decide what's in the best interests of that individual? The traditional family member? I think not.

People who are living with a disease such as HIV face more pain and suffering and humiliation and discrimination than you can ever imagine. We who work and advocate on behalf of people living with this disease spend enormous amounts of time and energy to empower people to take control over their own lives, to seek help and live in a society and province with respect and, most importantly, to live with dignity.

In closing, I strongly urge this government to hear what the vulnerable people of this province are saying. I

also caution—and I don't say it in a derogatory sense or as a threat, but in consultations with community groups in southeastern Ontario, whatever the opposition parties are doing, whatever the opposition parties are saying is being closely monitored. People in this province are frightened to death of what this present government's doing. They want a government that's going to stand up and protect them. They want a government that's going to protect the people of this province before the almighty dollar. Thank you.

**Mr Bulbrook:** Just to reiterate a bit of what Paul just said, it's not a political tactic; it's not generic criticism you would have as a citizen criticizing any party no matter who they are but just because they are the government. It's a sincere comment, and I hope the government of Ontario hears it, that you're scaring the people of Ontario. You are. You're frightening them. I hope you believe me when I tell you that. You're scaring people who live with HIV. You're frightening them. You're taking away housing, you're taking away social programs. You're doing enough to scare the hell out of a lot of people.

I hope you do believe that, when I tell you that. I'm not just being critical, running you down because you happen to be the government of today and last year it might have been the other party. This legislation, this bill, just puts more icing on the cake. The perception out there is that you don't recognize vulnerable people, you don't recognize the need for social programs, you don't recognize the need for things like rights advisers.

I hope you hear that. I'm sure today is not the first time you've heard it, and I don't think it's going to be the last time. Please don't change things because you're low in the polls; change them because that's what people elected you to do. As I see members around the table shaking their heads, I see that my words are not going too far with certain people, but hopefully, if you're not in power, you'll remember these words for the day you are. Thank you.

**Mrs Caplan:** Thank you very much for your presentation. There are a couple of points I'd like to make. First, I'd like to draw your attention to page 73 of the bill, where the hierarchy of who is called in as a substitute decision-maker includes the capable person's spouse or partner. Every interpretation we have had would suggest that this would permit a same-sex partner to act as a substitute decision-maker within that hierarchy.

My advice is that everyone—every adult, actually, but certainly the law permits everyone over the age of 16 to write a power of attorney for the purpose of personal care, and I think that's important. The only ones who supersede that hierarchy are guardians. You could have a situation where a family did apply for guardianship and that would supersede the hierarchy number 4. The second is the power of attorney, but the power of attorney does supersede even the guardian if there is a valid power of attorney in place.

I wanted to point that out to you. I did want to make sure you had seen page 73, section 4, and if you hadn't seen it, to know it is there, because I think it does address your concern. A spouse or a partner ranks ahead of family.

**Mr Bulbrook:** It may say it at some point, but as Paul said, this is a lot of reading and a lot of comprehension. I wasn't sure "partner" necessarily meant same-sex partner.

**Mrs Caplan:** My understanding is that it would. If there's any indication from the ministry that it does not, I would like them to say so now.

**Mr Parker:** I refer you to page 74. It's actually subsection (9) that continues the concept. I think that settles the issue.

**Mrs Caplan:** On page 74 it says, "Two persons are partners for the purpose of this section if they have lived together for at least one year and have a close personal relationship that is of primary importance in both persons' lives." That's the meaning of "partner." I think that's broad enough to cover the concern you've raised.

**Mr Bulbrook:** I'm not disagreeing that it's broad enough. I'm not sure it's specific enough.

**Mrs Caplan:** I think it's specific enough to cover—

**Mr Bulbrook:** Do you?

**Mrs Caplan:** Yes, I do. You can get other legal advice if you wish, and certainly the ministry would tell you if it wasn't, but I think that was the intention of those two sections together, and I wanted to point that out to you.

**Mr Marchese:** Thank you for your presentation. Just a few quick things, one mentioned by Mrs Caplan with respect to the fact that people can have a power of attorney and that would solve a lot of the problems. On the other hand, we heard of a case where this particular individual had AIDS and did a power of attorney, but in order to satisfy his parents he went with his parents in the last days of his life, of course with instructions that they notify the partner in terms of how things were going. The problem is they never notified him, and he died, even with the specific instructions he had left.

Part of the concern you're raising is how people with AIDS, gays, are often treated by family members. That's something that doesn't go away and we have to be concerned about that. I wanted to raise the point that even with a power of attorney, at times it still works against some individuals, depending on certain circumstances.

I agree with you that this government needs to take back its responsibility and protect the vulnerable of our province. I think that's true. My view is that governments have an obligation to take care of the people who are vulnerable. They say they care about that. Our view is that if they say, "We care about how we deal with vulnerable people and we care about advocacy," they have an obligation to tell us what they mean, and we don't know. And we should know that now and not after the fact, because after the fact, once this bill is repealed, we won't have a clue.

A number of people have agreed with you that to have simply one person as a member of the Consent and Capacity Board make a judgement on individuals is a problem. Many people, lawyers included, have appeared before this committee and are very concerned about having one individual make that decision. You're not alone in that view.

**Mrs Boyd:** Thank you very much for your presentation. It is my understanding, both under that section on

page 74 and again in the Substitute Decisions Act where they talk about a person having primacy, that a partner, as defined, is someone who's been with someone for a year and is important. That was certainly the description that was there before. I think you could put your mind to rest on that.

But I would think that it would be very appropriate for the Ontario AIDS Network to do some very hard work with all its member groups about the importance of a power of attorney, because someone may not be a partner; they may be a good friend who's the one you can depend on to support you. I think that those power of attorney issues are really important ones and that any advocacy group is going to need to be providing that kind of education for its members, certainly those who are advocating on behalf of people, as you do every day.

1430

**Mr Parker:** Let me begin just by completing the point that Mrs Caplan was trying to make with you. I think the answer to your concern on the subject of "partner" is to be found in section 18 of the bill. If you just pull together paragraph 18(1)4, subsection 18(3) and subsection 18(9), which is to be found on the other page, I think we've addressed the concern you've raised.

There's a recognition that people can become estranged from their families, for whatever reason, and they are more comfortable with a partner making a decision for them than some relative out there. With that in mind, a partner ranks higher in this scale than any family member, regardless of whether the partner is a spouse or otherwise, and the definition of "partner," as has been pointed out, is drafted to include partners of the same sex.

A person can become estranged from one's partner; we all know that. That matter is addressed also by the option of having a designated power of attorney, and the power of attorney ranks higher than partner. So a person who wants to be specific as to who makes decisions for him has the flexibility and has the authority to make that designation. That's guaranteed under the bill.

In the absence of that, we look first to a partner and then later we look to family members. I think if you read that provision, you'll find that your concern is addressed. I appreciate that it's complex. You think this is complex? Try the Income Tax Act some time, and that affects all of us.

I want to address just one other point that you made late in your presentation, your concern that somehow the government was allowing its focus on the budget to drive its agenda in this legislation. I want to assure you that is not the point with this legislation. This isn't a matter of trying to balance the budget at the expense of advocacy. This is to say that we think this Advocacy Act is the wrong way to go, and we're not alone in that thought. We have received thousands of deputations from people in the form of letters, phone calls, newspaper articles, editorials, columns, you name it, telling us that people out there don't like the existing Advocacy Act. They don't like what it does. The public guardian's office has received over 30,000 telephone calls, over 80,000 letters. So that is what is driving and is the motivation behind this bill—not balancing the budget, but a desire to respond to the people.



**Mr Waltenberry:** That's fine, Mr Parker. Who are the letters from? In Kingston, we serve a catchment area of 100 miles. When I worked for the Senior Citizens Council, we had 6,500 members. Last week when I spoke to the executive director of the Senior Citizens Council, the consensus of 80% of the members was that repealing this act is wrong. So I don't know what groups or what people you say wrote in, but I know many of the people in our area never wrote in.

**Mr Parker:** I recognize it, sir.

**Mr Garry J. Guzzo (Ottawa-Rideau):** It was too complex.

**Mr Waltenberry:** It is very complex.

*Interjection.*

**Mr Parker:** Garry, come on.

I recognize we will disagree on this point, as to whether we are doing the right thing or the wrong thing—

**Mr Waltenberry:** Well, why don't you get enough public consultation?

**Mr Parker:** —but I don't see any misunderstanding as to why we are doing it.

**Mr Waltenberry:** That's fine. You can twist it up by putting Mark through and asking us to refer to subsection, section—

**The Chair:** Excuse me. Mr Parker, your time is up. Gentlemen, the one half-hour is up. I thank you very much for your presentation here this afternoon.

I'd like to welcome John Gerretsen, the distinguished member for Kingston and The Islands.

#### MARILYN SMITH

**The Chair:** Our next presentation will be by Marilyn Smith. The floor is yours. You have one half-hour.

**Ms Marilyn Smith:** I come to you today as an individual, a concerned citizen, and that is largely all the biographical information I'll provide to you.

By way of introduction, much of the information available to the general public with reference to Bill 19, the Advocacy, Consent and Substitute Decisions Statute Law Amendment Act, 1995, including schedule A, the Health Care Consent Act, 1995, premises that current health care consent law is complex; intrusive in the lives of the vulnerably ill and their families; and further, anathema to treatment. Please refer to appendices A and B, which will be forthcoming.

Bill 19 would seem to represent an effort to reduce existing impediments to beneficent and timely intervention while safeguarding the autonomy and wellbeing of those who become ill, as well as those who may be incapable of making decisions necessary to preserve their health and general wellbeing. Notwithstanding, sections of this draft legislation may impede and in some respects negate its intended purpose. Recommendations are provided which may circumvent future instances wherein the rights of people, whether capable or incapable, and wherein the protection of incapable persons from emotional, physical or economic harm, are compromised.

With respect to the Health Care Consent Act, I will address specific areas of concern, immediately followed by a suggestion or potential remedy.

Subsection 2(1), definitions, under "treatment," clause (g): The omission of low-risk treatments from the broader definition of treatment which requires consent represents potential harm to patients. For example, in the anxious hours prior to a surgical procedure, or in the chaotic and emotional event of emergency, patients or their substitute decision-makers may not immediately recall or think to inform a practitioner of an allergy to medication unless prompted when consent is requested. The seemingly low-risk administration of a tranquillizer or painkiller could prove lethal.

Subsection 2(1), definitions, under "treatment," clause (h): Regulations defining things prescribed not constituting treatment could become an exhaustive list, given the variant determinants which may be utilized to categorize low-risk treatments. Health care providers treat multiple numbers of patients, each presenting with multifaceted considerations, in the selection and delivery of appropriate treatment. What may normatively be defined as low-risk may not apply to each patient. As the schedule lengthens, the potential for negative effect on treatment outcome and patient health could well increase. Further, while an intervention may be defined as low-risk, it may be a treatment to which the patient or appropriate substitute decision-maker objects to and would refuse if asked.

My suggestion: To minimize the potential for ill effect on the patient and to safeguard respect for patient wishes, omit subsection 2(1), treatment definitions, clauses (g) and (h).

Section 11, included consent: As drafted, this section may permit occasions where patients are denied the opportunity and right to give an informed consent to treatment. Including consent to variations or adjustments in treatment is to permit the conveyance of a blanket consent to undetermined treatments in undetermined settings. To date, consent, express or implied, has been subject to considerations specific to the treatment, not the uncertain or unforeseen.

My recommendation would be to omit section 11 to reflect the elements and principles of informed consent as they currently exist and as defined in section 10 of the Health Care Consent Act, 1995.

#### 1440

Section 12, plan of treatment: As in section 11, section 12 may give rise to situations where the practitioner proposing a treatment plan inadvertently may not convey significant facets of the plan, subject to the unique concerns of the patient. Blanket consent to any treatment or intervention at any time, in any place, by any practitioner potentiates the circumvention of informed consent. To reiterate concerns related to section 11, valid consent ought to be specific to the treatment.

My recommendation would be the omission of section 12 to again reflect the elements and principles of informed consent as they currently exist and as defined in section 10 of the Health Care Consent Act, or to develop specific requirements which ensure that in the delivery of a treatment plan there is compliance with section 10 of the Health Care Consent Act.

Clause 25(b), emergency treatment despite a substitute decision-maker's refusal, referencing the Health Care

Consent Act, section 19: Appreciably, the proposed legislation has been developed to minimize the potential for departure from a patient's capably expressed wishes, whether conveyed by the patient or an authorized substitute decision-maker. Ostensibly, an appointed substitute decision-maker would be far better acquainted with the wishes, values and norms of the patient—the principles for giving or refusing consent as outlined in section 19 of the Health Care Consent Act—than an emergency department physician. Ideally, a treating physician should never possess the authority to ignore a legal, capably expressed wish, decision or direction affecting a patient's life; that is, unless the person conveying the instruction is of questionable capacity. Pragmatism suggests there should be a legal means for physicians to treat a patient if a substitute decision-maker's capacity to understand or exercise the authority and dictums of the role is questionable. However, clause (b) provides no guidelines or parameters to physicians in utilizing the prerogative conferred in section 25. The authority is absolute.

My recommendation would be to amend clause 25(b) in order to ensure that in exercising this prerogative, a physician shall only do so when a substitute decision-maker demonstrates an inability to abide by the provisions set forth in section 19.

Subsections 34(1) and 34(3), applications to depart from wishes: The granting of a power of attorney or the possession of a statutory guardianship implies and confers significant assurance and trust that the substitute decision-maker will exercise his or her privilege with adherence and respect for the capably previously expressed wishes of the incapable person. In its current form, section 34 potentiates that this trust may be violated. Subsection 34(3) references the future advance in the likelihood of a positive treatment outcome since the time the incapable person has made his or her wishes known.

If it is apparent that the grantor's expressed wishes were based on medical information that indicated poor or insignificant outcome relating to the proposed treatment, the inclusion of subsection 34(3) is appreciably warranted. However, if the grantor's objections to a specified treatment were related to the treatment or the nature of the treatment itself, such an unchecked inclusion of authority is contrary to the dictums a substitute decision-maker must consider in executing an authority conferred in section 19 of the Health Care Consent Act.

My recommendations would be to amend section 34 to include a requirement that:

(a) An application to depart from wishes may only be made when it is apparent that the grantor's objection to the treatment was based on the anticipated treatment outcome at the time that the wish was expressed; and

(b) There is no reason to believe that the grantor's objection to treatment was premised on factors relating to the nature or method of treatment application or delivery, that is, the treatment itself, regardless of outcome.

With regard to subsection 35(3), application to determine compliance with section 19—those are the principles for exercising a power of attorney to consent to treatment—powers of the board: If, as stated in section 1(e), a purpose of the act is to ensure a significant role

for supportive family members when a person lacks the capacity to make a decision about treatment, subsection 35(3) markedly detracts from respect for the capable, previously expressed wishes of the grantor. Further, it does not foster the involvement of capable family members or friends of good faith in the care for an incapable person.

As discussed in the aforementioned section addressing concerns related to subsection 25(b), it is likely that a chosen substitute decision-maker is most familiar with the elements and principles related to consent on the person's behalf. That is, the substitute probably better knows the wishes, values and norms of the patient than would an administrative tribunal composed of persons not acquainted with the patient.

On an application for a determination of compliance with section 19, unless there is a written power of attorney which references the treatment application in dispute or the physician is aware of the patient's wishes and the information differs from the substitute decision-maker's instruction, it is desirable that the Consent and Capacity Board be primarily concerned with the issue of the substitute decision-maker's capacity to understand and exercise his or her duties as a substitute. Should the board determine non-compliance with section 19, it would be preferable that the board appoint a willing alternative substitute decision-maker to act on behalf of the incapable person, rather than impose state-sanctioned, bureaucratic intervention.

My recommendation would be to amend subsection 35(3) to reflect that while the board, in determining non-compliance with section 19, may substitute its opinion for that of the substitute decision-maker,

(a) it shall first attempt to exercise the powers conferred by subsection 31(7) to appoint an alternative representative, subject to:

i) revision of subsection 31(2), which as currently written would prohibit such an appointment; and  
ii) any other required revisions to section 35.

Areas of concern with respect to Bill 19, the portion dealing with the amendments to the Substitute Decisions Act, 1992, subsection 6(2), the repeal of paragraph 3 of subsection 10(2) of the Substitute Decisions Act, children as witnesses to power of attorney: The effect of permitting offspring of the grantor to witness power of attorney is to potentiate the grantor may be subject to duress. While many, or most, able to act under the authority of subsection 6(4), subject to subsection 6(2), would do so of good will and with regard to the best interests of their parent, the potential for conflict of interest, or the appearance of conflict, is contained in this section.

In the event that the grantor named an offspring as a power of attorney and the directive included an instruction or wish that ultimately resulted in the person's death, allegations of conspiring effort among siblings for the purpose of financial gain could well result, regardless of how ill-founded in truth the accusation may be. To delete this section in order to prevent an affront to the integrity and moral aptitude of loving children and to prevent unloving offspring opportunity to utilize witness of a



power of attorney in order to abuse their parent for the purpose of financial gain would only seem righteous.

My recommendation would be to omit subsection 6(2).  
**1450**

In addressing subsection 6(3), the repeal of subsection 10(3) of the Substitute Decisions Act, duty in the execution by witnesses: The elimination of the requirement that a witness bears no duty to consider the capacity of a grantor of a power of attorney could result in the abuse of an incapable person. On the pretence that it would be in his or her best interests to grant a power of attorney, a trusting person with no close family or friends may sign over all rights of property and person to any individual able to convince the grantor of their care and concern, though no regard for the grantor's wellbeing exists. Embezzlement, bankruptcy of the estate and deterioration of the living conditions of the vulnerable person could easily occur.

My recommendation would be the omission of subsection 6(3).

With regard to section 10, referencing subsection 16(6) of the Substitute Decisions Act, the public guardian and trustee's notification to the person of statutory guardianship of property: The wordage contained in subsection 16(6), "in a manner that the public guardian and trustee considers appropriate," suggests that the form of notification or the method of delivery of notification does not ensure that the affected person will receive notification in a comprehensive and timely fashion. A written notification faxed or sent by general mail to a visually impaired or functionally illiterate person may mean the person, while in physical possession of the document, has no independent means of ascertaining what it means. One may note that fax or general delivery to the person's residence does not ensure that the document will reach its intended destination or come into the possession of the addressee.

My recommendations would be to amend subsection 16(6) to:

(a) establish a time frame for notification; and

(b) permit that regulations be established to:

(1) ensure that special needs are to be considered in the drafting of the form in which notification is given; and

(2) provide guidelines regarding the method in which the notification is served upon the person to facilitate assurance of the receipt and understanding of the notification.

With reference to subsections 14(2) and 14(3), subsection 24(2.1) of the act, the appointment of caregivers as guardians of property: The ramifications of the inclusion of this section are exhaustive in the potential for undesirable effect, including the indefinite perpetuation of illness and reliance on caregivers.

Under the provisions of this section, the owners or operators of boarding-house businesses, which happen to be home for countless numbers of the mentally ill, could come into control of the finances of their tenants, as defined and regulated in the Residents' Rights Act.

Unfortunately, many residents come to believe that they will never be able to live independently. Frequently, they feel so little sense of choice or control over their

lives that they seldom consider there would be anyplace else to live. Essentially, they have no concept of themselves as customers who provide a source of livelihood to the owners, operators and employees of these residences.

Many of us would liken this living arrangement to a hostelry transaction wherein if we don't care for the accommodations, we check out and go somewhere cleaner, nicer or with more amenities, such as a swimming pool or sauna. Yet most residents of group homes don't consider that they have the right to take their business elsewhere if they don't like eating supper at 3:30 in the afternoon, don't have toilet paper or soap in their washrooms or don't feel they are treated fairly and with respect. The normal principles and practices of competitive business have little, if any, application in the domain of the group home.

My recommendation would be to omit subsection 14(2) and subsection 14(3), subsection 24(2.1) of the act.

Regarding section 27, a guardian or attorney may receive compensation above the prescribed fee scale: In circumstances where an attorney in the execution of his or her responsibilities of necessity incurs expense, either personally or financially, more than on average incurred by an attorney, it seems fair and wise to include this provision. However, it would seem equally wise to establish or allow for the future establishment of guidelines for accommodating such a request.

My recommendation would be to include in section 27 a provision for regulating the assessment and accommodation of a request for increased compensation.

Regarding section 28, the repeal of section 41 of the Substitute Decisions Act, which has the effect of making the availability of yearly financial statements no longer a requirement: Given that guardians and powers of attorney for property have the effect of giving control of the financial resources of one person to another, possibly unknown, individual or into the trust of an organization, it would seem just and reasonable to require that financial statements be available upon request.

Suggestion: Omit section 28.

By way of summary, I have no formalized, predicted conclusions, but I would like to comment that in reading newspaper articles and information that I've acquired regarding the introduction of this proposed legislation, there have been frequent references to the inordinate authority conferred upon the office of the public guardian and trustee, third parties, to intervene in the provision of treatment, essentially unwanted intervention in the personal life of an individual who is either suffering illness, has become incapable due to illness, or their caring family members and their caring family practitioners.

Unfortunately, this legislation still permits, and in some instances has broadened, the instances wherein a third or fourth party may intervene into the life of a vulnerable person or their family members who may wish to act on behalf of their vulnerable family member. The public guardian and trustee remains the guardian of last resort, as is the situation under the existing law, the Substitute Decisions Act. Powers of the board are such that it may substitute its own decision for that of substitute decision-makers of equal rank when they are unable to come to an



agreement as to the treatment that should be pursued or not pursued.

The availability of applications to depart from wishes without very stringent requirements and guidelines which dictate or guide the outcome of such a proceeding, and the introduction of care providers as potential guardians even prior to the appointment of the public guardian and trustee, is, in my opinion, possibly one of the most dangerous introductions that has been made: to introduce persons who may act on behalf of incapable people other than the state or employees of the state.

1500

Notably what is lacking from the proposed legislation is provisions for rights advice and/or advocacy services, and I see this as a fundamental requirement. Pragmatically, the provision of rights advice and advocacy services would have the effect of safeguarding the province against any litigation which may ensue if an individual was not informed of legal rights they possessed and ought to have been able to act on, but were not made aware of. For instance, in the current draft, when a family practitioner decides an individual is incapable with consent to treatment, there's no notification requirement. The only requirement of notification within this document of which I'm aware is that the assessor of capacity in making a determination of incapacity shall inform the individual of the finding. I may be reading wrong. They have the rights upon approaching the individual to instruct the person what they are there for, the potential outcome of a finding of capacity or incapacity, the right to refuse the assessment.

Further, one area to address is that I do find codifying the allowance for the provision of shock treatment for the purposes of aversive conditions to be distasteful. I would not want to be subject to shock or strapping or hitting if I was engaging in behaviour which someone else found offensive, but may be a source of comfort to the individual engaging in that act. But in that area, given that is a provision being platformed in this legislation, it would certainly seem prudent and wise and in the best interests of all concerned—the ill, the incapable, family members, care providers, whether formal or informal and government itself—to institute some provisions for advocacy and rights advice services.

**The Chair:** You are at the end of your time, Ms Smith, so there will be no time for questions. I thank you very much for taking the trouble to appear before us.

#### ALLIANCE FOR LIFE ONTARIO

**The Chair:** Our next submission slated is the Alliance for Life Ontario. For the purpose of Hansard, could you identify yourselves and then proceed.

**Ms Jakki Jeffs:** My name is Jakki Jeffs. I'm the executive director of Alliance for Life Ontario. With me is our legal adviser, Mr Geoff Cauchi.

We thank you for the opportunity to present before you today. We are the provincial coordinating body for 74 educational pro-life groups across the province and approximately 50,000 members within that group. We seek to promote, through education, respect for human life at all stages of development, from conception to natural death.

As I said, Mr Cauchi is joining me today. He is a lawyer by profession and our volunteer legal counsel. He's also current vice-president and director of education for St Catharines Right to Life Association. Mr Cauchi has given many presentations to our groups across the province concerning the existing legislation over the last year. He's also helped us develop a Judaeo-Christian, Pro-Life Power of Attorney for Personal Care/Advance Directive, which we have distributed to individual members of our local groups and made extensively available across the province at a nominal cost.

For your interest, we have included at the back of our brief in a white envelope a copy of this form, which we presume will soon become a collector's item once your work on Bill 19 is done, and whether it's passed with or without amendments. Be assured though that a second edition will be forthcoming from our association. It's complete with its extensive notes and it explains the beneficial options in the legislation to be embraced and the pitfalls to be avoided.

During the presentation given to you by our colleagues at Campaign Life Coalition, they recommended a public education campaign to ensure that people are aware of the dangers inherent in the typical living will type advance directives currently available on the market. This form was our contribution to public education on this issue.

I will be happy to help with the questions later on, but at this point I would like to turn our presentation over to Mr Cauchi.

**Mr Geoff Cauchi:** In addition to a written presentation from which today's presentation is drawn and our form of power of attorney, we have distributed to you a detailed legal analysis of Bill 19 in the areas of interest to our organization. This analysis contains over 20 specific recommendations, together with specific drafting instructions for the recommended amendments. The written presentation contains both an executive summary at the front and extensive end notes.

We want to direct most of your attention today to only a few of our issues, not because the others are any less important but because our colleagues at Campaign Life Coalition, REAL Women and Toronto Right to Life have addressed the others adequately, and our allotted time is of course limited.

The more I look at the current legislation and the more I talk to people who have been affected by it, the more I see its "one size fits all" approach as a fundamental weakness, not a strength. This weakness remains in Bill 19.

There are important public policy, legal and constitutional reasons why a presumption of capacity is appropriate for the adult population, but not appropriate for dependent children, why some forms of treatment require a higher standard of informed consent than others, and why some classes of health practitioners should not be given a broad, unreviewable authority to make judgments of capacity and administer the consent process. The failure of the legislation and its replacement, Bill 19, to make some very important distinctions puts children and vulnerable adults at risk of injury at their own hands or through exploitation by unscrupulous health practitioners.



The CTA and the HCCA embrace the radical notion that health practitioners in the abortion and family planning industries should have free access to other people's dependent children without their parents' knowledge or consent. It just so happens that it is this sector of the health services field with which we are most familiar and about which we can speak with authority.

It will become quickly obvious to you that, at least for today, we have placed our analysis of Bill 19 largely in the context of the provision of abortions and chemical contraceptives and abortifacients to minors. If time permits, we are prepared to answer questions from you on our recommendations in other areas of concern. I want to specifically invite you to ask us about our solution to the Lonnie Clements type of situation. I think we have something for you there.

Public schools in Ontario routinely, through staff nurses or public health nurses invited into the schools, refer young girls to the local birth control clinics operated by the county or region or Planned Parenthood. They tell the girls that the clinics will provide them with free contraceptives, or arrange an abortion for them if they get pregnant, and that their parents don't have to find out. They're told that the decision is entirely up to them and that they should tune out their parents' voices if they don't have an open attitude towards their sexual activity. The Ontario Association of Sexual Health Professionals actually boasts that they have been following a policy of secrecy since 1971.

At a time when a teenager is naturally trying to seek out his or her own identity, these kinds of messages are the ultimate weapon a salesperson can use to convince a teenager to do something their parents don't approve of. It's the kind of seduction that's as old as the serpent in the Garden of Eden, the kind that gives teens permission to go against the belief system of their family.

1510

Various sections of the HCCA, including the presumption of capacity for persons of all ages in section 3, and the right to rely on it, as well as the protection from liability clauses in sections 26 and 27, will combine to give a statutory blessing to the current practices of so-called sexual health professionals, and something akin to diplomatic immunity from liability for injuries that are inherent side-effects of their products and services.

We believe that section 3 has less to do with respect for a child's autonomy and confidentiality than with assuring the abortion and family planning industries unimpeded access to new markets for their products, services and ideologies; that is, other people's children. The duty of confidentiality is a creature of the common law, and under the common law it has never meant that parents should be excluded from decisions relating to treatment for their dependent children.

The standards for informed consent under section 10 of the HCCA assume an adult level of reasoning. Research demonstrates that it is extremely rare to find children and adolescents functioning at an adult level of reasoning. The contrary view that children are generally just as capable as adults with respect to complex medical decisions is a 1960s myth that has failed the test of science and human experience. A legal presumption that

is based on the exception rather than the norm is apt to do more harm than good, and as Mr Justice Cory of the Supreme Court of Canada said, "It has always been recognized in western cultures that children under the age of 16 require guidance and direction from parents and older persons."

Legal abortion and the birth control pill continue to be complex treatments with serious potential side-effects. The vast majority of adolescents are incapable with respect to these treatments because of their innate immaturity. Furthermore, the very fact that they are engaging in activity associated with these treatments may demonstrate incapacity. Gary Ingersoll of the University of Indiana says that if children are involved in sexual activity before age 16 they may have a "risk-taking profile" that parents need to address with professional help. We foresee that the HCCA will actually facilitate the treatment of many children on the basis of a self-consent that is not valid.

The majority of developmental theorists who accept the notion of developmental stages in the physical, emotional and cognitive development of children also support a role for parents in the healthy development of their child and the exclusion of the child from fully exercising his or her choices.

It may sound trite but it is true, hard cases make bad law. Dr Goldblum of the Toronto Hospital for Sick Children presented to you the case of the teen who was suffering from an STD but who could not overcome the fear of his parents discovering his condition in order to obtain treatment. This is a hard case. However, the statist notion that governmental power should supersede parental authority in all cases because some parents abuse and neglect children, or some children might avoid treatment for fear of discovery by the parents, is a concept repugnant to our culture.

Dr Goldblum told you that the majority of teens want their parents involved in medical treatment decisions, and that it is rare that parents are inadequate substitute decision-makers. What reasonable parent in this world wouldn't want treatment for their child upon discovering that he suffers from an STD? And even if you could find such a parent, that's the time for the health practitioner to make a call to the children's aid society, not take the law into his own hands.

We find Dr Goldblum's expression of support for the presumption of capacity at all ages, which will result in parents being excluded from treatment decisions for their children, completely out of whack with his own observations. But this kind of thinking is nothing new among promoters of liberal welfare state social policies. In 1987, the National Research Council in the US published a report called *Risking the Future: Adolescent Sexuality, Pregnancy and Childbearing*. The council specifically found a correlation between increased rates of sexual activity and provision of family planning products and services to adolescents, and even acknowledged that this may be a causal relationship. Notwithstanding this finding, the report continued to advocate higher government spending for contraceptive services for teens at low or no cost, unrestricted abortion and contraceptives for



teens without parental consent, condom distribution programs and school-based clinics.

Now, I say that when people propose a radical change to a centuries-old understanding of the proper relationship between children's rights, parents' rights and state power in response to an identified problem, we must challenge them to conclusively demonstrate that the side-effects will not be worse than the problem identified.

Dr Goldblum's suggestion that the section 3 presumption will help him to treat the teen with an STD is merely speculative. But even if we accept it for the moment, what good will it do him and our society if, for every such teen helped, he will have to treat an additional roomful of teens with STDs because the policy of secrecy has encouraged a whole new group of teens to rebel against their parents' rules and experiment with risky sexual activity? The response you often get to this objection is simply, "Well, we don't intend to encourage promiscuity," as if good intentions were enough to prevent it from happening.

What has been the effect of laws that require parental notification and/or consent with respect to medical treatment? Let's look at abortion and unmarried teen pregnancy statistics in those jurisdictions where this question has been examined. When Utah passed a law requiring parental consent for minors to be given contraceptives, not only did teenagers' use of family planning clinics and teenage abortions decline, so did pregnancy and birth rates. From 1980 until 1985, when the law was struck down, Minnesota had a law which required parental permission for a minor's abortion. During the five years in operation, there was a 21% decline in the rate of abortions, a 15% decline in the rate of pregnancy and a 9% decline in the rate of births among girls aged 15 to 17. There was a 23% decline in the number of abortions and a 15% decline in pregnancies in the second year after a similar law was implemented in Massachusetts.

Secret birth control pills and abortions for minors are not the answer to the unmarried teen pregnancy problem.

We've included in our written presentation a quote from Professor Kingsley Davis, the prominent population control proponent from the organization Zero Population Growth, hardly a pro-life source. In that extract, he blames intrusion by the state and its agents into the affairs of families for the problem, not the lack of access by teens to secret pills and abortions.

Elsewhere he has written: "The current belief that illegitimacy will be reduced if teenaged girls are given an effective contraceptive is an extension of the same reasoning that created the problem in the first place. It reflects an unwillingness to face problems of social control and social discipline, while trusting some technological device to extricate society from its difficulties. The irony is that the illegitimacy rise occurred precisely while contraceptive use was becoming more, rather than less, widespread and respectable."

This conclusion finds support in the work of an economist by the name of Jacqueline Kasun. She found that in every state in the US tested, increased government spending on programs that distribute family planning services to teens is correlated with increased levels of unwed teen pregnancy.

Bringing the matter back to Ontario, I suggest you review the findings of the city of Toronto public health department released in April, 1993, under the title Sexual Health Data Report. The report found that the overall pregnancy rate per 1,000 females aged 15 to 19 rose by 17% over the last 15 years. Furthermore, gonorrhea and chlamydia rates among males and females aged 15 to 19 showed significant increases in 1991 and 1992. No one could argue that there is any other community in Canada that gives teens more unrestricted access to contraceptives and abortions than Toronto.

We believe that the legislation can be and must be crafted to accommodate the treatment needs of the hard cases without abrogating the fundamental right of parents to regulate the sexual behaviour of their children as best they can.

I've spent the last 10 minutes trying to convince you why Bill 19's total rejection of parental rights is bad public policy, but the most compelling reason why the Legislature will have to make substantial changes is a legal one. The case of the Supreme Court of Canada in *R(B) v Children's Aid Society et al* has already been mentioned. The court in that case categorically rejected the notion that parental wishes with respect to treatment for their children can be arbitrarily dismissed as soon as the health practitioner decides that the treatment is necessary.

#### 1520

The HCCA cannot possibly withstand a Charter of Rights challenge because it arbitrarily, without notice, takes away parents' rights and delegates them to the child and his or her health practitioner. It does so whether a treatment is medically necessary or a mere lifestyle choice, as in the case of abortion and chemical contraceptives. Such interference in the child-parent relationship must be proven to be justified to a judge or judges before the treatment is administered. The HCCA essentially gives to individual health practitioners, including the school's 22-year-old staff nurse, more power to interfere in your relationship with your child than the local children's aid society.

A CAS can't act until it has proven to a court that a parent has refused consent to treatment that is medically necessary. The Supreme Court said that parental decision-making must receive the protection of the charter in order for state interference to be properly monitored by the courts and be permitted only when it conforms to the values underlying the charter. These values include respect for the family as an autonomous decision-making unit.

Five of the nine judges of the Supreme Court hearing the *R(B)* case, that is, a majority, held that the right of parents to rear their children according to their religious beliefs, including that of choosing medical and other treatments, is a fundamental aspect of freedom of religion guaranteed by section 2(a) of the charter. If a statute or other state action infringes upon that freedom, the state has the burden of proving to the court that the infringement is justified under section 1 of the charter.

Four of the judges also concluded that the liberty protected by section 7 also includes the right of a parent to nurture his child, to care for its development and to



make decisions for it in fundamental matters such as medical care.

On the subject of just how broad section 7 is, Mr Justice La Forest, one of the four, criticized the contrary opinion of the dissenting judges in the following terms, and this is very key; I don't think you've heard this part of the judgement before:

"Some of their remarks may be understood as supporting a parent's rights being overturned simply because a professional thinks it is necessary to do so. I would be very much concerned if a medical professional were able to override the parent's views without demonstrating that necessity....

"Here, what is attempted," that is, the contrary approach, "is to limit a right by another, with no stated mechanism for judicially determining just when, on the facts, the first right is overridden." This is very important, this part coming up. "To get a fuller appreciation of what this means in the present context, one need simply postulate that the act impugned here, with all its inbuilt protection for parental rights, did not exist, and was substituted by an act that made no provision even for notifying parents when some state agent decided a certain treatment was necessary for a child."

One can only speculate if Mr Justice La Forest had in mind the Consent to Treatment Act when he spoke of a hypothetical statute, but each, meaning the Consent to Treatment Act and the HCCA, does exactly what he said could not be justified under the charter. In our view, as they are currently written, neither the CTA nor Bill 19 could survive a charter challenge by a parent.

The next objection: The HCCA treats all treatments above a *de minimis* level the same. But in reality, not all treatments are the same. Some require a higher standard of care from health practitioners in administering the informed consent process than others. Recreational or lifestyle treatments, which are proposed for socio-economic reasons and not for the treatment of a disease or an injury, but which carry a high risk of injury, require special consideration. Abortion and the birth control pill fall in this category. Subsection 5(4) of the Consent to Treatment Act should be re-enacted in the HCCA to give the government the power to impose higher standards where abuse of the informed consent process is identified.

The assumption implicit in section 9 of the HCCA, that all health practitioners are able to make reliable judgements of a child's capacity to make his or her own treatment decisions, is not realistic. In 1992, the Ontario Association of Children's Aid Societies told this committee:

"Many of the health care practitioners who will be required to make such judgements have neither the training nor the knowledge of child development such that their judgements could be considered informed. Many encounters with health care practitioners about individual treatments are very brief and are not conducive to the health care practitioner developing a knowledge of the individual child before them, such that their judgement could be considered informed."

We wholeheartedly agree.

Finally, it would be incredibly naïve to expect health practitioners, who have an institutional, economic and

ideological bias in favour of the treatments they are selling to children, to make objective judgements of capacity. Health practitioners in the family planning industry are notoriously biased in their approach to supplying abortions and chemical contraceptives and abortifacients to minors. They readily use their positions as platforms for social engineering. Their commitment to an ideology is so strong that regulatory control over their compliance with section 9 is not sufficient.

The clandestine relationship between sexual health practitioners and their child clients is marked by conflict of interest and unequal bargaining power. Expecting such health practitioners to comply with the HCCA is like expecting a Chevrolet salesman who is trying to sell you a Lumina to outline all the best features of a Ford Taurus. It just isn't going to happen.

Our recommendation, therefore, is that health practitioners not be permitted to make judgements of capacity of unmarried children who are under the age of 18 and living under the care and control of their parents.

I think we'll stop there and invite questions. As I said, we have a list of recommendations. That's summarized in the executive summary beginning at page 4, and so we invite questions about that or any other matter.

**Mr Marchese:** I thank the presenters for their submission. I'm not sure that my colleague has any questions.

**Mrs Boyd:** No.

**Mrs Johns:** I just wanted to talk to you about the R(B) case that you talked about in there. It's my understanding, and I'm not a lawyer so I know you'll be able to correct me on this, that the child they were talking about in that particular case was an infant and the parents had the right to be able to make decisions for an infant because the infant was obviously incapable of making those decisions. That case wouldn't necessarily proceed through to be the same precedent, I suppose would be the right word in legal terms, for someone who was deemed to be capable and could understand the procedure and what the outcomes would be of that procedure. Is that correct?

**Mr Cauchi:** No, I don't think that's the reading of the case. I think you should perhaps get the staff to analyse the Child and Family Services Act, as well as that decision, very carefully. It's in general terms: Parents have the rights. You have to have some kind of mechanism, maybe not exactly the same mechanism as in the Child and Family Services Act, but you must have some mechanism whereby parental concerns can be addressed. There must be fairness in the procedure.

It's remarkable, the Child and Family Services Act, section 105—and this deals with people who have had their children taken away from them, they've been accused of sexual abuse. It says right in there that they retain the rights to make medical care decisions for their children, whatever rights they had, even though their kids may be taken away from them. So how could you give them those rights, respect those people's rights, and deny them to people who are ordinary citizens who have not been accused of any kind of wrongdoing in respect of their children?



I am a member of the board of directors of my local children's aid society and I am proud to work under that statute. It is a wonderful statute because it balances parental rights and children's rights and the state's rights very delicately and very well. I'm just flabbergasted that this statute completely ignores those principles. As I said, I'm very proud and I respect the procedure that is in that statute, and I think you should really give it hard consideration, because this statute, sooner or later, if it's passed this way, is going to be challenged very easily. If you think that people in the past have been abandoning the public education system, once they have an idea that their daughter could be sent to an abortion clinic during the school day, they're going to avoid those schools in droves.

**The Chair:** Your time is up, and I thank you very much for making your presentation here today.

Mrs Johns, I think you meant to say it was obiter dicta and I think we confirmed that that statement was obiter dicta. Ms Swift will have the case for us in the event anyone wishes to review it.

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#### ONTARIO ASSOCIATION FOR COMMUNITY LIVING

**The Chair:** The Ontario Association for Community Living, Nancy Stone, president, and Audrey Cole.

**Ms Nancy Stone:** I'm Nancy Stone, president of the Ontario Association for Community Living. I am a parent of a young man who has an intellectual disability. I'd like to introduce Audrey Cole, who is a board member of OACL and also a parent of an intellectually disabled young man. Audrey is also our resident expert on this subject and has worked since 1988 on the issue and is certainly very capable of presenting and has been instrumental in the brief that you have before you. I'm going to turn it over to Audrey, after also introducing Barbara Thornber, who is our executive director at OACL.

**Ms Audrey Cole:** You will see that our brief generally covers five areas: why guardianship discriminates against people with intellectual disabilities; it talks about a different way of thinking, a different legal paradigm, that would make the necessary accommodation to that disadvantage; it also talks specifically about how Bill 19 puts people with intellectual disabilities in even greater jeopardy of losing their fundamental right to self-determination than is presently the case; it addresses specific concerns in Bill 19, including the repeal of the Advocacy Act, which we believe is unconscionable, the Health Care Consent Act and significant amendments to the Substitute Decisions Act. There's a separate document which includes the particular recommendations and suggestions that OACL has to make, which is literally pulled out of the main document. All of them relate in some way to the issues of rights, of accountability and of the other safeguards which will be removed by Bill 19.

As to why guardianship disadvantages people with intellectual disabilities, any legislation ever that's based on a cognitive definition of capacity is bound to disadvantage people with intellectual disabilities. It's a disadvantage that's not faced by any other adults on reaching

the age of majority. In that context, we believe that it's discriminatory.

The particular effect on people with intellectual disabilities of labels like "incapacity" and "incompetent" can become self-fulfilling in reality. The damage to self-respect and social image can be very crucial in how people treat people—"treat" in the broad sense—with intellectual disabilities. There's no evidence of benefit under guardianship to compensate for the diminished human value and status that it represents as far as people with intellectual disabilities are concerned. It doesn't make you less vulnerable.

The main benefit of guardianship is to third-party interests, and it's quite clear that those are the interests that are driving this bill. The government is ignoring its obligation to accommodate in the legislation for that disadvantage faced by people with intellectual disabilities. There is an obligation on government to build legal ramps to guarantee access by people with intellectual disabilities to their fundamental right to self-determination. Bill 19 not only takes them away but, by doing so, it increases the threat and the jeopardy in which it puts those particular people.

What's needed is a different legal paradigm that recognizes the natural way that human beings make decisions: We do it with the help and support of the people who are around us. The fact that we do it and we enjoy that privilege doesn't change our status; it doesn't say we're incapable. But people with intellectual disabilities are subject in society to having their capacity questioned anyway, and so it has a different effect on such people than it does on the majority of people.

The law has to correct the misconception that capacity lies within the individual, ie, that it's a cognitive kind of thing, and acknowledge that capacity depends on the support we have around us and the environment in which we have to function. The law has to recognize ultimately, in order not to be discriminatory, that as adults we make decisions interdependently, not independently. The Substitute Decisions Act didn't accommodate, and Bill 19 doesn't accommodate either.

Guardianship's an instrument of control. People with intellectual disabilities don't need control. Our whole movement is about how they're emerging from centuries of control, neglect and abuse, caused in turn by fear, by hatred, by ignorance, apathy or disinterest. It's our purpose in our association, our movement, to support them in taking their place as citizens who have an equal right to be there, an equal right to participate and an equal right to contribute. They feel very threatened by laws that make guardianship easier. They don't need control; they need support. They need support and respect, and accommodation to lessen the disadvantage that they face in society.

We're going to deal with some specifics in the bill which cause us a great deal of concern and are picked out from the ones that are in the separate document and in the main bill. All of them deal with the taking away of rights that the bill represents, the reducing of accountability that the bill represents, all things which are going to have a particular effect on people with intellectual disabilities.



**Ms Stone:** I'm going to speak to the section of our brief on page 12, electric shock for purposes of aversive conditioning.

We all have fundamental rights. Section 12 of the Canadian Charter of Rights and Freedoms states that everyone has the right not to be subjected to any cruel or unusual treatment or punishment. Subsection 43(5) of Bill 19 in fact would provide the legal authority for an action that, without that amendment, would be a violation of the Criminal Code. This committee must be fully aware of the seriousness of this amendment. By making shock a treatment under this amendment, there is nothing to stop its being recommended under the Health Care Consent Act, where any family member could approve, without any court approval or independent review, and that could result in a person being subjected to a lifetime of shock treatment under the guise of aversive treatment.

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The total absence of any safeguards against its use in this legislation is totally unacceptable. Security of the person under section 7 of the charter includes the freedom from your own self-inflicted injurious acts as well as the injurious acts inflicted by other people. You cannot choose either/or between these two acts but must choose alternatives to the injurious behaviour.

OACL believes very strongly that, at the very least, Bill 19 must be amended so that the authorization of the use of electric shock as aversive conditioning will require a hearing either by the court or by the Consent and Capacity Board. This practice is so controversial, not happening anywhere else in Canada, and, in OACL's view, so dehumanizing that no one should ever have the authority on their own to provide a valid consent to its use. Thank you.

**Ms Cole:** In addition to that, there are a number of other issues that we also see as infringing on people's rights and providing less accountability than is present in the current act. All of our concerns here don't make us any happier about guardianship as a concept, but we are conscious of the fact that opportunity wasn't taken this time to make those accommodations so we will be left with the same kind of traditional guardianship legislation that will continue to disadvantage people with intellectual disabilities.

We have great concerns about some of the changes and removal of some of the accountability with respect to powers of attorney. The fact that more immediate family members can be witnesses, the fact that witnesses now will only have to attest to the fact that a particular person signed it means that what could happen would be that you can have a situation, and this is not unknown, where immediate family members could actually conspire to draw up a power of attorney, persuade the so-called grantor to sign it, provide the necessary witnesses, all irrespective of the capacity of the grantor to sign it in the first place. That causes us great concern. It's a tool for manipulation without the safeguards that were there before.

We have great concerns in the Health Care Consent Act about the sort of extended consent concept with respect to plans of treatment. Two major concerns: The more items of treatment that get added into a long plan

of treatment, the harder it will be for a person with intellectual disabilities to keep in mind what has been consented to. The longer that plan is, the more individual components it has, the harder it's going to be for people.

You can imagine too with a person with an intellectual disability the difficulty that some practitioners already have in finding out how to communicate with people with intellectual disability becomes even worse when you're going to have a long plan of treatment. What we're saying is that no treatments anywhere in that line should be done without actual consent. In other words, for someone who perhaps isn't able to manage the idea, and very few of us will be, by the way, the long plan of treatment, then it should be obligatory on a practitioner to get consent at every step of the way. Surely that should be there for all of us. We need that safeguard.

The other thing in plans of treatment that is very frightening for us is the issue of "do not resuscitate" perhaps being the last item on a plan of treatment. We've included in the brief—I forgot to note the pages—some quotations, some references to the inquests, the Christopher Robin inquest particularly, which is relevant here, a quotation from the Stephen Dawson case in BC in 1982, all of which are relevant because of the fact that many, many people do not place the same human value on people with intellectual disabilities as they would on themselves and other things interfere with the kinds of decisions that would end up with a DNR.

Already there are parents who believe that they ought to have authority to say, when a person enters any kind of group home or other place than the personal home, that they should be able to give advance consent that should there be an emergency, the son or daughter would not be resuscitated. Surely that's one of those things in life that no one in advance should be able to give for anyone except themselves. It's unacceptable that those kinds of decisions might appear in a long-term plan. They really should ever only be addressed at the time that it becomes an issue. We would like you to consider that.

Now, those aren't the only ones, but in view of time, those are the only ones we're talking about here.

The other thing that is of particular concern to us, of course, is the repeal of the Advocacy Act. The whole 10 years that people with disabilities and their representatives worked to try and get a mandated system of advocacy was simply because it's so difficult to have effective advocacy when abuse and neglect and those kinds of things are taking place unless you have authority to get in the place and do something about it, and by repealing that act, that authority will disappear. Anything that's going to replace it, if it's to have the same effectiveness, will have to have exactly the same requirements, so it doesn't make sense to us that it was repealed. As a matter of fact, we just consider it unbelievable.

There also seems to be some confusion raised in Hansard about people not understanding what advocacy is, particularly I might say on the government side, so we've helped you perhaps in the brief to understand a little bit about what advocacy really means.

Ever since there have been people and systems that have assumed power and control over other people, there's been advocacy. There have been victims in those

and there's been need for advocacy. Advocacy's about enabling people to reach out for their own dreams and a little warmth and respect in their lives. It's about caring and about the kind of society that we want to live in. It's about bringing some heart into a callous, crass, materialistic world. It's about human dignity.

There's probably never been a time in Ontario when there's been more need for advocacy for vulnerable people than there is today, for all sorts of reasons. To repeal the act is unconscionable, but it won't stop advocacy. It won't go away, because advocacy's about truth and justice and humanity.

I think that because of the time, that's as far as we can go in an oral presentation. We've tried to express all of our concerns in our brief. We would entertain any questions.

**Mr Ron Johnson:** We had a presentation from the Brantford and District Association for Community Living and we had a presentation from a parents' group that's a part of that association. I have two questions. The first one is, do you find that most associations have parents' groups involved with them?

**Ms Cole:** I didn't catch the names of those associations. These are associations for community living?

**Mr Ron Johnson:** Yes, at the local level. Many of them, from my understanding—I know the one in Brantford does—have a parents' group that does work on behalf of all the residents. I'm asking, the associations within your organization, do most of them, to the best of your knowledge, have parents' groups associated with them?

**Ms Cole:** Additional to those that are already part of the association?

**Mr Ron Johnson:** Yes.

**Ms Cole:** Some may do.

**Mr Ron Johnson:** I guess what I'm getting at is, we're finding through a number of submissions that there is a large number, whether it be parents' groups or advocacy groups that are in communities now.

**Ms Cole:** Yes.

**Mr Ron Johnson:** Of course, the coordination doesn't seem to be there among them all, but there are a number of advocacy groups within communities across the province. Our goal of course, since we do support advocacy, really is to enhance that and to encourage that. I know you are opposed to the repealing of the Advocacy Commission and the Advocacy Act, but are you—

**Ms Cole:** I didn't mention the commission, I mentioned the act.

**Mr Ron Johnson:** No, the act; I understand that. When the act goes, so does the commission. What we're talking about is tapping into a lot of the resources that are already available, and I want you to give me your opinion on what our role as government should be, keeping in mind the goals that we have.

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**Ms Cole:** Thank you for the question. Your role as government, it would seem to us, would be to fulfil your obligation to ensure that there is sufficient legislation to enable advocacy to take place in an effective manner. If you look back in our history to the situations in which we've known of abuse in homes for special care, in

unlicensed boarding-homes, all over the place, there is no access. People in the sort of organization you're talking about can't get in. There's no right of access. That's the whole purpose of the Advocacy Act, to give the authority for advocacy to take place in a way that would get people out of those situations.

The simple question is, that's an obligation. It's an obligation that only government can meet and it's absolutely essential that whatever takes place after now has that authority.

**Mrs Caplan:** Thank you very much for an excellent brief. I'd like to address your recommendation that disputes between equally entitled surrogates be referred to the Consent and Capacity Board when they can't agree. I think that's an important one because right now, the way it stands, if children or parents and children who are lumped together in one don't agree, then the public guardian and trustee steps in, and I think that an intermediary step might be a helpful one. Do you support having the Consent and Capacity Board's decision—this is on page 3 at the top—being final, or should they act as a mediator where they can't—

**Ms Cole:** I think what we were concerned about here is that there's a very clear public role for the public guardian and trustee as the last resort decision-maker and the mandatory investigator and so on of situations that can't be dealt with otherwise. Since some of those things would go to the Consent and Capacity Board, others would go to the public guardian and trustee, surely to avoid conflict of interest for the public guardian and trustee it would make more sense for all of those situations to go to the Consent and Capacity Board.

**Mrs Caplan:** It's my view that if they also took parents and children out of the same category in the hierarchy, you'd have less chance for conflict, although if there is an equal number of children, you're going to get disputes. I think it's an interesting point that you make.

The other one I wanted to ask you about, I think that you've raised an issue of training which is important. Evaluators and capacity assessors are two very different species, and there is no requirement for the training of evaluators.

**Ms Cole:** That's our concern. There is no training for evaluators, so what comes into the evaluation process is everybody's values and historical baggage, which probably has nothing to do with anything but always affects decisions unless you can have some kind of standardized process. That's why we suggested the capacity assessment offices, simply because they've done a superb job in focusing on the real issues so that the extra stuff stays out of those decisions.

**Mrs Caplan:** Would you agree that in fact evaluators would not need the same kind of comprehensive training as a capacity assessor for the purpose of guardianship—

**Ms Cole:** No, we're not suggesting they need the same training. We're saying that's a probable place because they've already worked through how you separate what you have to really evaluate from all of that extraneous stuff that tends to mixed up in it.

**Mrs Caplan:** I think that's a really good point. The last one that I draw your attention to is the fact that



you'd rather have the public guardian and trustee than a caregiver. It would seem to me that the real concern there would not be someone who was employed on a straight salary but a caregiver who would benefit by ordering things in a fee-for-service relationship. Would you have an objection or would you amend this to say that where the caregiver was in a fee-for-service relationship or where they would materially benefit by being the substitute decision-maker or the guardian?

**Ms Cole:** Well, the context was service providers. That was the context of that, was it not?

**Mrs Caplan:** But the context of service provider doesn't necessarily mean fee for service. For example, you could have a nurse who is caring for the patient, she's on salary, she has nothing to gain by looking after this. Her natural tendency as an advocate on behalf of her patient might make her a very appropriate person. I think that's perhaps what the government was contemplating, but I would not want to see anyone who was in a conflict-of-interest situation—

**Ms Cole:** And that was the issue we're trying to get at, was the conflict of interest.

**Mrs Caplan:** So would you agree with that as the conflict, where you would benefit by the care you would provide?

**Ms Cole:** Yes. We have to bear in mind that you could have the bizarre situation whereby a service provider not only is, professionally and with remuneration, responsible for the care of the person, is part of the system probably that's done the evaluation to enable the person to be in the place in the first place—not only do they have control of the assets that are needed to care for the person—whatever cost it is, they have control of that—but now we have the additional bizarre idea, by adding possibly under regulations that you can get paid for personal care decisions, that the same person could be paid to be that guardian. If that isn't conflict of interest on top of conflict of interest, I don't know what it is.

**Mrs Caplan:** I think that has got to be clarified.

**Mrs Boyd:** Thank you very much for the very lucid description of changes that you would see made. I think you certainly have very eloquently presented the case in terms of the need for advocacy in many of these areas, and as you know, we certainly agree with you. While we would agree that there may be other ways of doing it, the need for advocacy and the need for government support of advocacy, the right of entry and the right of access to records is minimal in order to really do the job. All we have to do is look at the number of cases in which an inquest is the only way in which someone's situation—the Kendall or the Christopher Robin home inquests—and knowing the detail of those is enough to make one's blood run cold.

I'm very pleased to see that you recognize the real difficulty we face when the government wants to take aversive therapy away or allow it completely, a compromise suggested that there at least be a hearing by a court or a capacity review board. I think, given their determination, that may be the only kind of protection that's there. But I would agree with you it's minimal and definitely at the very least.

Certainly we work together in terms of that whole issue and I think the conflicting vision that's been presented to us—we get one psychologist saying, "Oh, it will only ever be used for one person," and another saying, "I treat hundreds of people this way and obviously hundreds of children would benefit"—gives you an idea of what we're looking at. So I think this may be indeed the only way in which to get the situation looked at in a detailed, case-by-case kind of situation.

On the issue of the "do not resuscitate" orders, this has been mentioned to us before for both physically and intellectually disabled people. We know only too well that it is very hard often for health professionals to look at individuals apart from their disability and to make assumptions about what quality of life means. We've been resisting any issues around quality of life because it's such a double-edged sword for individuals, and your support of that is very helpful.

In all of this, is it your sense that what has been presented in Bill 19, with the exception of the repeal of the Advocacy Act, is fixable, is able to allay some of the fears of some of the changes that you've suggested were to be accepted by the government?

**Ms Cole:** I suppose any bill is fixable if there's a commitment to fix it. I think that many of the proposed amendments that we've addressed in our brief shouldn't happen at all because they're going to be detrimental to at least one part of this population, a part that in fact has equal rights but is not always given the opportunity to exercise those rights. Were there a recognition on the part of government of its obligation not to further disadvantage people with intellectual disabilities, any of them could be fixed.

**The Chair:** Thank you for your submission today.  
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#### FAMILY ASSOCIATION FOR MENTAL HEALTH EVERYWHERE

**The Chair:** The next submission is the Family Association for Mental Health Everywhere, Judy Wallace and Eileen Boyd. Welcome.

**Ms Judy Wallace:** Thank you. As an introduction, I'd like to say a few words about FAME. FAME is a family association for families in which someone experiences serious mental illness. We're a community-based organization with branches in Metro, Durham, York and Peel regions at present. Our membership is open to all families regardless of diagnosis, family situation or position.

We've been involved in mental health planning since the days of the Graham report and are currently involved in district health council steering committees, provincial advisory committees, mental health reform work groups, and have made presentations to the legislative subcommittee on numerous bills.

We recognize that one's place in a family has a strong impact on what one wants to see in terms of legislation. The position of parents is very different from that of spouses. Those who are siblings assuming a support or custodial role are different from an adult child looking after an aging parent. However, we feel that all families face similar dilemmas in attempting to secure appropriate



treatment, coping with the symptoms of mental illness and understanding a complex and difficult system.

Many of our families have faced impossible situations when attempting to get help for their ill loved ones. Sometimes the legislation has helped, sometimes it has hindered, and sometimes it has just confounded us.

Although families must deal with very difficult situations on a day-to-day basis, it is important to remember that families must also face the long term and what will be available for their loved ones when they can no longer provide. It's easy to argue, "Put me in charge and I'll take care of everything." It's more realistic to say, "Give me the tools and the support to help my relative to become self-sufficient and maintain that status."

Through the process of mental health reform that started under the Graham report, families have been acknowledged as a vital community resource and partner in the planning process. Prior to the downsizing of the psychiatric hospitals and hospital restructuring, families provided over 60% of the community care for consumer-survivors. With greater pressure on fewer resources, families have had to assume a greater role.

Each new piece of legislation sets up a whole new format, expectations and procedures. This in itself presents major problems for families because access to information has always been one of the greatest barriers that families face in working with the mental health and related systems. It's critically important that information, education and support around this latest piece of legislation be mandated in the act and that someone be delegated to ensure that this happens. That will at least ensure that consistent information gets to everyone concerned: health care professionals, consumer-survivors, families, police, courts, public guardian and trustee, and anyone who feels they need it.

Independent rights advisers would be the ideal, from our perspective, as a parallel to the provincial psychiatric advocates' office. The next-best option would be to entrench that obligation in the duties of the Consent and Capacity Board.

I cannot emphasize strongly enough how important education and information about legislation is to families. If families cannot easily access clear information, how can they be responsible attorneys for their vulnerable relatives? Would you expect another group to act without appropriate tools? It's a simple but necessary request: Mandate someone to ensure that those affected by and interacting with this legislation have access to materials and people to assist in understanding. Pamphlets can be displayed in all the places that government brochures and information are usually available, as well as hospitals, doctors' offices, community agencies, pharmacies, libraries. But it must be there.

We see this bill as a mixed blessing. It provides some very badly needed changes, but then adds some items that cause us great concern. Like most community organizations, we struggle to understand the language of legislation and do our best to translate the wording into ordinary language that makes sense to us. Some of this presentation will be questions to you for clarification.

The good news for us is that the definition of "capacity" has been enlarged to include an understanding of the

consequences of refusing treatment. So often in the past, individuals with serious mental illness or a mental health problem were only presented with one half of the equation: "Do you understand the proposed treatment?" If the answer was yes and the person refused to comply, that was the end of the discussion and usually the end of the hospital stay.

An additional provision that will assist families is the security of the power of attorney. The process required to withdraw the authorization will for some make it a more onerous document. However, it's important that the power of attorney hold through a crisis and not be withdrawn mid-episode.

Profoundly ill but experienced patients have been released because the definition did not require them to understand and appreciate the consequences of their actions. Sometimes they were released to the street in winter, with no resources or supports, not because they weren't available but because the time to put them into place was not available.

We would propose instead that the assessment be made by one of the following, who would be the choice of the grantor: his or her own psychiatrist, psychologist, social worker or case manager, who has a history with the person and will not interpret idiosyncratic behaviour as lack of capacity; or, if the individual would prefer, an assessor on the prescribed list.

Once the certificate of capacity has been issued and a copy given, the grantor may complete the power of attorney and outline his or her specific circumstances and requests. The power of attorney, along with the certificate of capacity, would then be taken to a notary public, who would swear that he or she had seen both documents, ascertain that the grantor was aware of what he or she was signing and that he or she was the person about whom the power of attorney was written. Copies of the certificate and the power of attorney would then be given to the person named as attorney, and presumably the grantor would keep one for himself or herself. End of process—neat, simple, manageable, and doesn't cause people to walk away with frustration.

There are existing instances in law in which individuals may sign away rights and privileges with no need to certify anyone's capacity. Pre-nuptial agreements and marriage contracts are common documents in which one person agrees to conditions that are different from what the Family Law Reform Act would provide.

I recognize that in these powers of attorney you may be signing away charter rights and that is a slightly different aspect, but if you make this a very onerous task, people won't do it and then they'll be stuck and we'll be back to the same situation we've had all along.

All families are asking is that the process be simple, straightforward and possible in a few steps without much cash outlay. Our experience with clause 50 is that obtaining the Ulysses clause is more difficult than freeing Ulysses from his bonds.

I understand the rationale for excluding low-risk treatment from the bill, but it seems to create a complication that could be eliminated if substitute decision-makers signed an authorization, much like parents do at the beginning of every school year, that authorizes a facility



to provide a variety of treatments as needed. In my experience, that meant that when the children fell and cut a knee, I wasn't called to approve the treatment, but I was called for a broken bone.

Perhaps I missed the definition or limitation of "low-risk" and assumed that it covered a predictable variety of non-invasive care. However, as I thought about it, I wondered if it could include the use of restraints or isolation in a psychiatric setting. They are restrictive but not invasive and therefore could be low-risk. I would prefer to ensure that controlled and regulated acts are not included in this range.

To return to the question of rights advisers, as families we have found that the advocates' office in psychiatric hospitals has been helpful to many of us. We're not all lawyers or mental health professionals, and I do not think an adviser employed by or provided by the institution about which one needs advice is objective or free enough to be very helpful. I want someone who will be knowledgeable and on my side if I need that sort of help. After all, we're very clear about ensuring that those facing the judicial and correctional systems know their rights. Why should it be less for those facing major health decisions? Does incapacity reduce one's status to less than citizen and less regarded than an accused in a criminal case?

1610

Families are not happy about the Advocacy Commission for a variety of reasons, not the least of which was an apparent anti-family bias, but this feels like going from the sublime to the ridiculous. It should be possible to provide a moderately priced program and, as I said before, put it under the auspices of the Consent and Capacity Board, but please don't leave us in the dark.

I'm also concerned about the lack of requirement to notify the person that he or she has been deemed incompetent with regard to treatment prior to administering treatment. In my brief, I've given an example in my family, but I would like to say that if you're dealing with people in a psychiatric setting and one of their diagnoses happens to be paranoia, which is fairly common, and you try to treat them without explaining to them what the situation is, you are doing nothing but exacerbating their paranoia and you're going to get much worse behaviour and much poorer response than if you talk to them at the beginning.

I would ask that health care providers be obligated to inform the patient of the determination of incapacity, the impact it has on treatment, the patient's right to a board hearing, and to provide the appropriate forms. The attempts to make life easier for the substitute decision-maker or guardian are generally appreciated, but I don't understand lifting the requirement to make a statement. The form was a tangible reminder that the substitute decision-maker was making decisions for another person and taking responsibility for those decisions. I don't believe I heard anyone object to the requirement, and I think it's helpful, to have reminders of your roles in another person's life. This also provides another opportunity for education and clarification, as a health care provider can reiterate the substitute decision-maker's obligations under the Health Care Consent Act.

I must admit to being baffled and bewildered as to why electroconvulsive therapy has been specifically

reinstated in treatment. As a treatment about which a constant controversy seems to exist, what is the need to provide it with seeming legitimacy by special mention? There do seem to be some instances in which, as a last resort, it may be indicated. However, provide a protocol that will ensure that all other available treatments have not been effective, that the person is a serious risk unless the ECT is administered, that the substitute decision-maker understands the possible risks, and that the facility is authorized to provide this treatment and has the authorization of the board. I mean the Consent and Capacity Board, not the board of directors.

I'm also concerned that although aversive therapy is discussed, I did not see any standards or controls defined for its use. I understand that a situation in Hamilton underlined the need for standards and controls. Those people who experience severe head injuries and are subjected to cruel and unreasonable aversive therapy will now require more therapy to both undo the damage and provide the skills that were apparently being taught.

The act seems to be attempting to streamline everything. I'm not opposed to greater efficiency so long as it doesn't leave people feeling out of their own lives. The Consent and Capacity Board will be making a great many decisions about people's lives. An appeal procedure is in place under a very tight timetable: seven days. It seems only civilized to provide the individual with the necessary means to determine the efficacy of an appeal rather than waiting most of the appeal time to get a decision and rationale in writing. This courtesy seems reasonable, given that treatment will continue during the appeal anyway.

We're aware that this government feels that user fees will provide the economic support needed to balance the budget. However, I'm concerned that in a request or an appeal to the board, one side has access to all the pertinent information while the other side must pay to examine or copy the material which is their own records. It does seem to weight the scales in favour of the hospital and leave particularly those in limited economic circumstances with an inadequate means of defence.

In addition, it would seem that, while deemed incompetent and receiving disputed treatment, the individual must not only pay for his or her records but find a lawyer, get a legal aid certificate—if it's still available—and put the presentation together in seven days. That would be a challenge for someone who's apparently competent. Please don't trample on people's rights and access to those rights in the name of efficiency. If an incompetent patient in a psychiatric facility is faced with this process and the barriers, it will hardly make them feel confident that his or her best interests are at heart.

What is needed is a mechanism to assist the person to understand as well as they can and to feel supported and cared for, not railroaded. I don't know about you, but when medical personnel have tried to force me to take drugs or treatment without my cooperation, I'm not a happy camper, and I've not been diagnosed with any serious mental illness or deemed incompetent.

Powers of attorney for property and personal care are important concepts that enhance the individual's taking of responsibility for himself or herself. If you plan ahead



when there's no impending crisis and work out ideally what you'd like to see happen, then you and your substitute decision-maker can feel confident that when the time comes your wishes will be carried out.

However, it's important that these documents are an expression of the person and not the overenthusiastic wishes of caregivers who may be tired, frustrated and focused on their own situation. We know that most families provide wonderful loving care, but we also know that 100% of any group is not perfect. There are families who through their own circumstances may push their own needs ahead of their vulnerable relative. The safeguard is a requirement for independent witnesses. It's not perfect, but it at least makes a philosophical statement about the intent of the document.

There are also situations in which there are no family members who may act as attorney or guardian. Elderly residents of nursing homes may not have anyone left who lives within a reasonable distance. Some immigrants and refugees have no family in Canada, and perhaps no family left. Although the operators of care facilities are often very attached to the residents of their facility, that is not the case in 100% of situations. Please remember the inquest into the death of a former Queen Street Mental Health patient who was residing in a home for special care and who was bludgeoned to death by a staff member of the facility.

As a safeguard to those residents and as a safeguard to the good operators, do not put them in a position of also acting as attorney. It's a dangerous precedent, fraught with potential abuse.

The bill does provide, however, a positive step for those who have found themselves under the public guardian and trustee when a suitable guardian is available. There have been instances in which finding of incapacity meant an automatic referral to the public trustee. When families then tried to become the guardian, the cost of the application to court became prohibitive, as most people were quoted \$5,000 to administer a disability pension. The provisions that permit the transfer from the public trustee to another suitable guardian will simplify that process and assist families.

On the other hand, there are instances in which the nature of someone's illness makes family guardianship very difficult and controversial. In those instances, families need the option of the public trustee. It is also positive that guardianship can apparently be split, with the public trustee assuming fiscal guardianship and the family assuming attorney for personal care, for instance.

It's also critical to provide for those periods when an individual who experiences serious mental illness is incapable as well as for those periods when he or she is capable. The nature of the illnesses as chronic means that individuals are always on a continuum from illness to wellness. The provisions in the Mental Health Act have always provided for that contingency. Many other chronic illnesses also have the impact of producing periods of incapacity that can be short-lived—thyroid conditions, diabetes and others.

This bill discusses the assessors and evaluators, but the definition of "treatment" seems to exclude these categories and the work they do. Part of our concern is the

cost of these assessments. Under previous legislation, an assessment for the purposes of establishing capacity could cost between \$150 and \$250 an hour for what could possibly be a four-hour session. The cost of \$600 to \$1,000 to determine that one was capable of assigning a substitute decision-maker is prohibitive and makes a mockery of the law.

I'm not clear about the process required for determining capacity. The act says that it presumes capacity for everyone. Does that presumption apply to those with a history of mental illness? If not, then what needs to be done? Is it the same complex system of hiring a capacity assessor from an approved list and passing a checklist of questions? Is the certificate of capacity then provided to the individual on the spot or sent in the mail?

On the other hand, this legislation does not discuss the cost of an assessment at all. Once again, we are between the sublime and the ridiculous. An independent assessor will take more time to assess an individual whereas the psychiatrist of record or other therapist should be able to make an assessment based on historical knowledge as well as the current situation. If in fact the intent is to fairly determine capacity to assign an attorney, then surely the process should not be financially prohibitive so that only those well-to-do mentally ill will have the option while the rest have to be content with the public trustee.

#### 1620

Once we have determined who should be the substitute decision-maker and ascertained that the role is currently necessary, the new act provides for only one free chance to prove one's competency. After the one chance, it then becomes a matter before the courts. How does someone who is in receipt of a disability pension afford the cost of a court appearance? Surely we're creating a class system in which those who can afford the assessors and the courts are able to argue their cases, while those who have little means because of their illness are penalized. Is this the Ontario we wish to create? I hope not.

I must admit to some amusement in the section that covers access to records. For most families, getting the most barebones information has been a herculean task. The bill now proposes that anyone who makes application for guardianship should have access to records. Ladies and gentlemen, I know of situations when a facility would not even tell a family member that their son or daughter was a patient because it breached confidentiality, and now a mere application permits full access? I would implore you to think out what you're saying before this bill becomes an act. Yes, families want and need more and better information than is normally available. Yes, families would like to be able to discuss their perspective with medical professionals. Yes, families would like to be consulted before decisions are made that affect them, like discharge to home. But to shift from no information to full disclosure to an applicant for guardianship seems a little extreme.

We would recommend that good communication occur between the guardian and the attending staff, but that guardianship needs to be established first and that consideration be given to extending that courtesy to family to whom the patient will be returning to live.



Under section 1 of the bill that revokes the Advocacy Act, we have some concerns. Although the act was not considered to be family-friendly, it did ensure that there were standards for advocacy and rights advisers, which seem to have disappeared. For instance, the bill states that volunteers who are acting out of good faith cannot be held liable. That frankly frightens me. I could cite numerous examples of well-intentioned volunteers who have advised vulnerable people to take a course of action only to find that it has very deleterious effects. Are we now expecting very vulnerable people to operate under the philosophy of "buyer beware"? If that is the case, then, ladies and gentlemen, I am appalled. How often has a government tried to protect older women from the schemes of con artists? Are we abandoning vulnerable people to a worse fate?

I'm equally appalled that the legislation exempts professionals and volunteers from liability if they were acting in good faith. Are we to believe that if a medical, judicial or other type of professional acted in good faith and the impact of their actions resulted in damage to the person or death, it's all right? That being the case, there's no longer a need for liability insurance, because what professional is going to say they acted in bad faith? Please consider the implications of this clause. Recourse to civil suit must be available to cover cases where good faith is not enough. If that recourse is removed, then we are all at risk. And like the joke about cars produced on Monday mornings and Friday afternoons, I wouldn't want any medical procedure on days and times when, despite good faith, the medical staff may not be up to scratch.

Volunteers are also exempt from liability if they acted in good faith. Are we putting vulnerable people in situations of risk with no recourse because somebody who wants to help, perhaps from their own agenda, creates a greater mess? There is no lack of horror stories about vulnerable people acting on the instructions of a well-wisher and ending up ill, in danger or in situations that they had not anticipated. I've given you two examples of that, examples that we've dealt with in our office and tried to mop up in the last couple of weeks.

Many organizations have been acting as advocates for vulnerable people for a long time. Case managers are often advocates. In our organization, the supportive visitors act as advocates, public health nurses, home care workers and the list goes on. We are liable if we provide the wrong advice. We are liable if we foul up and we should be held to account. I do not believe that anyone should not be responsible for what they say or do. Please don't legislate that option.

One final concern: The bill seems to provide a means by which the public guardian can recoup expenses from vulnerable people. Ladies and gentlemen, what cost comes first? Rent and food or recovery for time spent dealing with a client? In many cases, those placed under the public trustee have had concerns about funds, real or imagined. That may result in numerous phone calls and face-to-face interactions. Should someone on a disability pension pay even the nominal rate of 50 cents a call on an already very limited income because their illness prevents the ability to trust a bureaucracy? Please consider that cost recovery may result in an inhumane system

of penalizing the disabled and poor to show a balanced fiscal budget. The costs may be higher in the long run.

The bill also provides for physicians to go to the board for determination if the attorney refuses to agree to treatment that the doctor feels is necessary. If the attorney is acting on the wishes of the incompetent person and those wishes were made during a period of competency, except in an emergency would this be necessary? If new treatment was developed after the power of attorney was executed and the document was not updated to reflect this, surely the doctor and the attorney can discuss this, go to mediation or find some form of resolution. The bottom line, however, should be the person's expressed wishes. If they aren't respected, why bother with the power of attorney at all?

In conclusion, this bill provides some elements that families have been lobbying for and dreaming about for a long time. But if the cost of gaining the provisions for attorneys for personal care is the acceptance of many other provisions, then it's an expensive piece of legislation for all of us and will have expensive repercussions in the long run.

I would hope that the intent of the Health Care Consent Act is to provide people with the opportunity and the means of providing their own care when they're unable to make decisions on the spot. My fear is that it will provide a means of control for very vulnerable people that will backfire in the long run as their attorneys age and are unable to provide the structure and support that is needed.

Ms Boyd is now going to talk about her concerns as a family member.

**Ms Eileen Boyd:** With the advent of the new government, we family members gave a sigh of relief on hearing that the Advocacy Act, Substitute Decisions Act and Consent to Treatment Act were being reviewed, and hopefully simplified to facilitate help for our loved ones. Our hopes were raised when we read that the new act strengthens the role of families in making decisions on behalf of incapable relatives. In the words of Attorney General Charles Harnick, "It minimizes the role of government in people's lives and puts decision-making in the hands of individuals and families."

With relief we read the words of the Minister of Health on November 22: "The legislation will hold the advance directions of an individual and existing power of attorney with the highest regard. Only in situations where someone has absolutely no connections will the state step in. We've taken significant steps to revise the previous government's legislation to allow the family to make substitute decisions for loved ones without unnecessary bureaucracy. We have established a workable streamlined process for admitting an incapable person to a care facility."

Hearing all this, we gave a sigh of relief. And to the credit of the new legislation, improvements have been made in many areas, but in the area where I would choose to focus, which affects many in our organization, I still find we are left with unworkable procedures which sound good on paper but which will not work, thereby leaving many needy people without access to the streamlined method of getting help.



I refer to the Substitute Decisions Act, section 50, which sets out the requirements for a special provisions power of attorney. This, as I understand it, would enable a substitute decision-maker to have a family member taken to an institution for help if the grantor had pre-stated these wishes at a time when he or she was in a capable state of mind. This legislation we applaud, as it provides the necessary care and protection which would expedite the return to normalcy.

Many who suffer with mental illness have long periods when they're capable and can instruct a substitute decision-maker to take over the decision-making during any relapses when they may become uncooperative, paranoid, confused, obstreperous, lack judgement and descend into unreason.

These pre-stated directives must include the temporary sacrifice of certain rights: the right to change their mind in a crisis, the right to a review board hearing, which would delay treatment, and the right to freedom. These rights at this time are impediments to a speedy recovery and their suspension is not unreasonable under the circumstances. We're not taking our unfortunate relative to the guillotine; neither are we incarcerating them in the mental institutions of the past, though this legacy still affects our thinking. In fact, we are availing them of the best help we know at present and we are following their pre-directed wishes. All this is at present, as I understand it, in the act.

1630

However, this ideal procedure will not work for some and will not be utilized by many needy people. The requirement of assessment of capacity before a power of attorney with special provisions becomes effective will be the stumbling block on which it fails.

Firstly, the perceived affront to an often vulnerable personality in having to have their capacity formally assessed before they can make such a document: People who succumb to mental illness often have short tolerance levels, high irritability and very short fuses. Anyone who deals with them will know the personality problems to which I refer. To willingly submit to an assessment in their good periods is not an easy requirement to fulfil, thus making the legislation unfeasible.

Secondly, the finances of such people are often in short supply as they struggle to build their lives in their productive times. To suggest a visit to an assessor at the \$80- to \$150-an-hour rate charged is a final blow and deterrent to action.

We are well aware of the legal concerns for this assessment in case of later contestation but would argue that this requirement of proof of capacity is not a requirement in other—

**The Chair:** Excuse me, Ms Boyd, your time is up. That is the one half-hour. We must proceed. I'm sorry. We've got another problem—we might go later today if it is decided.

**Mr Marchese:** It's only a minute and a half.

**Ms Eileen Boyd:** It's only one minute.

**The Chair:** We've already gone over the 30 minutes by one minute. I'm sorry. We have your written statement and we can conclude it. I thank you very much for

your presentation today, and I'm sorry I had to interrupt you, but we have no choice.

We have before us a Mr Lillico of the firm of Lillico, Bazuk and Kent. He's from Peterborough. He is here on the wrong day, through inadvertence. He's supposed to be here tomorrow. Tomorrow is his birthday. I'm asking your indulgence at this time, not to hear him now but at the end of the day for 10 minutes. He has a written brief and he's agreed that he could highlight it for 10 minutes, which means sitting after 5:30. Is there agreement for that? Thank you.

**Mrs Johns:** We'll have to sing Happy Birthday to him.

#### DIXON HALL NEIGHBOURHOOD CENTRE

**The Chair:** Our next organization is the Dixon Hall Neighbourhood Centre, Mr Toby Druce.

**Mr Toby Druce:** When I timed my comments this morning, it was only 10 minutes, so perhaps that'll allow the other gentleman to step in.

Good afternoon. My name is Toby Druce and I'm a community development worker for Dixon Hall Neighbourhood Centre, a non-profit, community-based organization. Dixon Hall is located in the southeast corner of Toronto and includes Regent Park, Canada's largest subsidized housing complex, in its catchment area. Our organization serves the very young, under two years old; the very old, over 90; and every age, race, culture, class and ability level in between.

While the proposed amendments to the Substitute Decisions Act and the Consent to Treatment Act are disturbing and indicative of a giant backward step in terms of our commitment to the rights of the vulnerable members of our society, I will be confining my remarks today only to the intended repeal of the Advocacy Act.

Let me begin with the Oxford definition of advocacy. Oxford describes advocacy as the process of pleading in support of a person or policy. It goes on to describe it as the function of an advocate, and it describes an advocate as one who supports or speaks in favour of a person or policy; one who pleads for another.

It's significant that both words are nouns. They name a person, the advocate, and a thing, advocacy. This naming is important because it helps to define advocacy and the advocate, thereby taking the process and the person out of the realm of abstract philosophical debate. "Advocacy" is a venerable term that has long been recognized as an essential component of a just and equitable social order.

Advocacy and the role of the advocate is not unknown to any of us. Perhaps the most readily available example is that of the lawyer. When we hire a lawyer, we are in fact hiring an advocate, someone with a specialized body of knowledge who can represent us and our interests.

We expect, in hiring that lawyer, that they will have access to and will collect all the information they require to represent us; they will inform us of our rights and responsibilities; they will prepare our case and take instruction as to the execution of that case from us; they will defend our rights in court; they will communicate with us as to the impact of any decision made that will



affect us; and they will continue to take instruction from us until the case is concluded. These are the essential steps of any good advocacy.

In recognition that everyone is entitled to an advocate in the legal system, we as a society decided to ensure that everyone, regardless of their ability to pay, would have an advocate available to them if they required one. Further, through legislation, we decided on a set of minimum standards that all legal advocates must meet in order to be called lawyers. Of course, not all lawyers are good advocates, and certainly not all good advocates are lawyers. However, the process of advocacy and the skills and abilities of the advocate do not change, regardless of the context in which either is carried out.

Many advocates are non-regulated practitioners of the art of advocacy, and this is not necessarily a bad thing. It allows for increased access to an advocate by those who require one. Questions of access are central to any discussion on vulnerability.

Our lawyer friend in the previous example has a right to access her client and a right to access the information that will be presented in court by the prosecution. Similarly, the client, as discussed earlier, has a right to a legal advocate regardless of their ability to pay and the right to refuse or change their appointed advocate if they so choose.

Unfortunately, the same rights of access do not exist for those who desire a non-legal advocate. I want to be very clear that I am not suggesting that all advocates should be lawyers. There is a crucial role for advocates outside the legal system in resolving disputes prior to an individual seeking legal remedies to their situation.

Resolving problems before turning to legal recourse is a win-win solution. The already overburdened court system is relieved of additional cases and the cost savings to all stakeholders, especially government, are substantial. Most important, though, is that a vulnerable person has had their rights ensured in a timely fashion. Such swift action can often be the difference between life and death, as in the case of Joseph Kendall or Marion Post. If you're not familiar with their cases, then I'd refer you to *Advocacy: Now More Than Ever*, page 2, the last paragraph.

In order for an advocate to be effective and to faithfully discharge their responsibilities, they require access to certain kinds of information and participation at certain steps of any decision-making process. An advocate without due access is like a box of chocolates: You never know what you're going to get.

The Advocacy Act was the first time the role of non-legal advocates was clearly spelled out in legislation. The act provided advocates with the tools they required to do the job. It also ensured the accountability of the tool users. The act established an independent body that was charged with delivering advocacy services province-wide.

As an institution of the government, the Advocacy Commission maintained its accountability to the people of this province through their elected representatives. As an independent body governed by representatives from consumer groups, the commission maintained accountability to its clients. By reducing its operating expenses by over 50% in the first year of operation, the commission maintained its financial accountability to the tax-

payer. By its commitment to enhancing the effectiveness of existing groups, it demonstrated its accountability to its own ideals of fostering partnerships, improving access, equal representation and elimination of costly duplication of services. I would challenge this government to find another example of a government agency that has done so much with so little.

Vulnerable people have a right to be heard and to have their wishes respected when it comes to making decisions about how and where they will live. The Advocacy Commission provided people with the information and assistance they required to make informed decisions about their lives. In the absence of such a body, there are no guarantees that people will have access to the information they require to make sound decisions.

Vulnerable people have a right to access an advocate who can provide them with information and who can plead on their behalf. The Advocacy Commission had the tools to ensure that this process was available.

#### 1640

Vulnerable people have a right to an advocate who is competent and who clearly explains his or her role, who is accountable to a higher power and who is explicitly instructed to take direction from the person who requested their services. The Advocacy Commission could have built people's confidence in this regard had it been given the opportunity to complete the ground-breaking work it had done in consulting with client groups across this province.

Accept that vulnerable people exist in the province of Ontario. Accept that vulnerable people have the right to be heard, to access the information and decision-making processes that affect their lives. Accept that people have the need and the right to an advocate who can assist them understand and exercise their rights. Accept that the advocacy system provides a net cost reduction to Ontario's taxpayers by avoiding costly legal actions or, more sadly, inquiries into fatal cases of abuse or neglect. Accept that an individual requesting the services of an advocate has a right to expect that the advocate will be well trained, well supervised, well experienced and equipped with the tools she needs to do the job right.

Accept any of these things and you must accept that the Advocacy Act and the resulting commission is the best, most accessible, most affordable and accountable system ever created anywhere in the world.

If you members of this committee do not believe that vulnerable people in Ontario require an organized system of advocacy, then I encourage you to visit with any group in your constituency that deals regularly with children, with women, with seniors, with parents, grandparents, sons, brothers, sisters and daughters. The documented cases of people in vulnerable positions being abused is legion. The undocumented cases are infinite.

To accept the myths that advocacy is bureaucratic, expensive, intrusive or destructive to families is to accept a lie. As political representatives, your task is to make decisions that are in the common good, not simply politically expedient. Ontarians need an organized, accountable, rational and affordable advocacy system. We have that in the Advocacy Commission, and to let the



commission die would be an inexcusable affront to the people of this province.

With the Advocacy Act and the resulting commission providing so much to Ontario, it seems inexplicable that a proposal exists today to eliminate it completely. Not since the Avro Arrow have Canadians had such an opportunity to lead the world in innovative design. The Arrow died as a result of backroom politicking and in retrospect is seen by many as the great missed opportunity of the 20th century. How sad it would be if we have not learned from our mistakes.

With respect to recommendations, rather than unnecessarily repeat the recommendations put forth by the Advocacy Commission, I will state here that I urge the committee to consider, as a minimum, accepting in full the recommendations put forth in this document, *Advocacy: Now More Than Ever*.

If you have questions, I'd be happy to answer them.

**Mr Marchese:** I want to thank you for your presentation, Mr Druce. The work of Dixon Hall is well known throughout Toronto and I'm sure throughout Metro, and parts of Ontario, I suspect, so you come here with a great deal of credibility in the field.

I think you've described advocacy very well. I think you've defined it very well in the many pages. It's sad that it should take that long to have to convince some members or many members of why we need it, but it has to be done over and over again.

You make the case about needing an organized system of advocacy, because if it's not organized, we have a problem. "Ontarians need an organized, accountable, rational and affordable advocacy system," and then you make a point about why we need the commission as well.

The argument makes the case that we don't need this kind of advocacy. By that they mean that there's some other kind of advocacy, on which I'm not certain what they mean. Some other members say it shouldn't be institutional; it shouldn't be governmental. It should be left to families, individuals and organizations. Mr Johnson will say: "But you're doing a great job, Dixon Hall, of doing advocacy for the folks. Isn't that great. How can we support you to do that better?" That's the kind of question you're likely to get.

Can we do it without the Advocacy Act, without the commission, without rights advocates, and if so, what can we do to help you?

**Mr Druce:** Theoretically, anything is possible and you could do good advocacy without the Advocacy Act and without the Advocacy Commission. But in order to be good advocates you need to have in place the tools to get the access to information and to decision-making that the Advocacy Act provides and which is not available anywhere else.

I respect that the government is keen to give the tools to its transfer partners to accommodate the kinds of things its transfer partners need to do, and advocates are no different really. To do the work that we do, we need to have good tools, those tools being legislation that ensures, on behalf of the people we are working for, that we have access to information we need to inform them.

**Mr Marchese:** The act gives people the right of entry, which means that where there are cases of abuse, some-

one has the right to enter, observe, identify and then have authority to deal with the problem. Do you have right of entry? Do your organizations have right of entry at the moment so they can help abuses where they observe them or see them or hear them?

**Mr Druce:** No, we don't. I guess it always begs the question, who will guard the guardians? Without some legislation in place to ensure that people aren't at risk by our having that right of entry, I'd not be comfortable taking that on.

**Mrs Boyd:** Just very briefly, I want to share with you that more than 30 years ago I was sent as a volunteer to Dixon Hall by my youth group and learned a lot of the things I know about the need for advocacy and the need for the kind of work you do there. I'm glad to see, this many years later, that the enthusiasm and the clarity around the need for advocacy is still there among the staff. Congratulations.

**Mr Ron Johnson:** Mr Druce, I want to thank you for your presentation. My colleague Mr Marchese is right: I will commend you on the work you do at the Dixon Hall Neighbourhood Centre. I think all the type of advocacy work that is being done by local organizations at the grass-roots level should be commended and should be encouraged. I want you to know that really is the goal of this government, to foster that kind of commitment to the vulnerable.

It's really not about building a big \$18-million bureaucracy to deal with advocacy, because that doesn't work. What we need to do is to approach this in a different manner that will encourage friends, family, volunteers, existing organizations, and that's really where we're going with this.

We've been criticized by Mr Marchese in the past for not having a plan ready now. What we want to do is go through a consultation process to develop that plan. We want to hear from people like yourself who have valuable input, who work in the field, who understand what advocacy's all about before we develop a plan. If we brought a plan forward now, we would've been criticized because we didn't consult.

That's where we're coming from. We're consulting now. We want to hear what you have to say. We did two and a half weeks of stakeholder consultation at the ministry; now of course another three weeks of consultation. We will be coming forward with a plan for advocacy in the province of Ontario, and that plan will be coming forward in a few months. I want you to understand where we are, and the reason there's not a plan on the table now is that we wanted to consult first.

My question to you is this, and again Marchese's right in what I'm going to ask and he asked it a bit himself: When we bring forward some policies with respect to advocacy in the province, help me understand what your role would be in terms of your organization, how we can help you do what you need to do in terms of providing advocacy, and not just you but other organizations in the province as well that are currently in place and currently providing that kind of service.

**Mr Druce:** Speaking for myself, as somebody who is a social worker working in the social services field, I would say that the best thing you could do to help the



clients I see would be to bring back the Advocacy Commission, because that's what we asked for for a long time, to have a body like that, not at \$18 million a year, but then my understanding is that they didn't need to spend \$18 million a year either and they brought the money down.

**Mr Ron Johnson:** I think that's a valid point. I think you have to understand that we have, for example, the proposals from the Advocacy Commission that we are looking at, and we're looking at very closely. I want you to understand that we take advocacy very seriously, and that we are going to look at all the proposals that come in and put a plan in place that's really effective and involves family and volunteers and existing organizations, and get rid of the big government bureaucracy this province has been plagued with, not just in advocacy but in government in general.

**The Chair:** Thank you very much, Mr Druce, for your presentation.

1650

#### UNITED STEELWORKERS OF AMERICA

**The Chair:** Our next submission is the United Steelworkers, Carolyn Egan and Dan McNeil. Welcome at the end of a long day.

**Ms Carolyn Egan:** Thanks very much. My name is Carolyn Egan. Sitting beside me is Dan McNeil. We are both here representing the United Steelworkers of America.

Some of you might be asking yourselves why a union like the Steelworkers would take the time to make a submission on the Advocacy Act, and I want to outline what those reasons are and what our perspective is.

First of all, we are here because of the work we do. I myself am a health care worker. All Steelworkers don't work in mines or steel mills. There are nearly 1,800 health care workers organized by my union. Dan is the chairperson of the Steelworkers retirees association. He represents nearly 10,000 retired members of our union in Ontario. We both know from experience that seniors and chronically ill adults make up a huge number of the vulnerable population in this province, and it helps us and our union to understand the importance of advocacy.

We also have an interest as union members. We know what it's like to have in place an effective and very powerful advocate on behalf of working people. We look to our union to defend us, to assist us, to speak for us, to educate us, to empower us, to ensure our dignity, our safety at work, our rights, and to better our daily working lives. We know that is a real struggle and it helps us to understand the need people have for advocacy in this province, because alone it's extremely difficult. When you're together or have someone working on your behalf, it makes the whole process an awful lot easier.

Finally, we also have an interest as ordinary human beings who live within families and communities in this province. Both of us, and I'm sure all of you, know people who are developmentally disabled, who are psychiatrically disabled, who are physically disabled, who have terminal diseases, who are elderly and frail, who live in institutions, who are infirm or chronically ill.

These are our friends, our family, our neighbours, our associates. Although we love and care for them, many of us live impossibly busy lives, particularly women with child care responsibilities. We work. We have very little time, and as much as sometimes we would like to, we are very much unable to meet their special needs or be there when they need us. That helps us, I think, to understand the urgency of advocacy and why the Advocacy Act was such an important tool and resource for people in Ontario.

In this province today, there are more vulnerable people than ever before. The economic crisis has created a circumstance where there are many, and most estimates range as high as half a million. We think our society should be judged by how we treat these vulnerable members of our community.

I think everyone in this room knows it's no secret that in our view, the Steelworkers' view, the record of the current government, we do feel, is nothing short of shocking.

Cutbacks to welfare payments have reduced the real income of thousands of people who rely on general welfare or family benefits. User fees under the Ontario drug benefit plan have added a new cost for seniors and people with disabilities. The threat of a revised definition for disability leaves many anxious about their eligibility for pensions and access to dental, drug and extended health care plans.

The repeal of the Employment Equity Act effectively puts an end to job opportunities and accessible workplaces for the disabled. Cutbacks to education have inevitably removed the money for assistants and assistive devices in the classroom. Cutbacks in legal aid threaten the rights and abuse protection relied upon by many disadvantaged people.

Massive reductions in transfer payments have severely limited access to transportation for the disabled. The downloading of services and costs to municipalities have closed community programs designed to reach out to and integrate vulnerable people. Bed closures at psychiatric hospitals and institutions for the developmentally challenged have left many, literally, on the street in the absence of any community support.

The cancellation of co-op and non-profit housing slammed the door on vulnerable people waiting for accessible and affordable accommodation. Cutbacks in emergency housing or shelters leave little room for seniors or people with disabilities who have been abused in an institution or in their own home.

All of these government actions abandon, we feel, vulnerable people to marginal and unfulfilled lives, marked by poverty, isolation, unemployment, abuse and discrimination. Each government action, alone and collectively, is a mark of shame, in our view.

If these things are done in the name of cutting government spending, then they are unbelievably shortsighted and mean-spirited. If they are done in the name of lowering income tax, then they pander to selfishness and consumerism. If they are done in honour of reducing the deficit, then they are guilty of ranking the lives of human beings beneath the bottom line of a balance sheet. That too, in our view, is a mark of shame.



In the midst of this frenzy of government cutbacks, all of which have had a terrible impact on vulnerable people, it comes as no surprise to us that this Conservative government has also decided to repeal the Advocacy Act and dismantle the Ontario Advocacy Commission. It's no surprise, but on behalf of ourselves and our union, we have to say that it's hopelessly wrong and we have to oppose it.

We know we are not alone in this opinion. We have read other briefs presented to the standing committee by the Advocacy Centre for the Elderly, the Toronto Mayor's Committee on Aging and the Ontario Coalition of Senior Citizens' Organizations. These groups have provided thoughtful and detailed criticisms about the changes which the current government wants to make to the Consent to Treatment Act and the Substitute Decisions Act. They have also registered their protest at the elimination of the Advocacy Act and the commission. We join these groups in their concern and urge you to look carefully at their advice and their recommendations.

These acts were the products of decades of studies, reviews and reports. They came into being as a response: to horror stories coming out of care institutions; to adults nearly dying of dehydration, malnourishment and neglect; to lurid headlines about elder abuse; to tragic deaths of street people freezing in bus shelters; to cases of over-medication, unnecessary interventions, crippling use of restraints.

**Mr Dan McNeil:** Hundreds of consumers and service providers helped to give shape to the legislation and the commission. I can attest to that personally. As chairperson of the Steelworkers Organization of Active Retirees, I helped distribute the proposals and information to thousands of our members. We even held a conference and the centrepiece of the discussion was the purpose, objectives, implementation of the three acts.

I was also the co-chair of the Ontario Coalition of Senior Citizens' Organizations, an organization that represents 80 associations with a membership of over 500,000. In that capacity, I participated in many discussions about the acts and heard a great deal of feedback about their relevance to seniors and significance in their lives. I can say without hesitation that all three acts received widespread acceptance. Seniors across Ontario expressed their relief that finally all the talk was over and something concrete would be done.

That's why I'm so bewildered at the exercise we're having here today. The one thing that's been missing from the debate so far is any compelling or even plausible reason why the government is doing all this at such a great cost to the rights of the most vulnerable people in our society.

We would submit that the answer is found not in any principle, but in who benefits from those changes: the medical profession who will no longer have to be concerned about having to defend their decisions in the face of well-informed review; operators of health care institutions whose treatment of their patients or residents will no longer face public scrutiny; families who are prepared to make choices in their interest rather than in the interest of their vulnerable relatives, and we all know that happens. In short, everyone involved in the care of the

vulnerable in our society except the people directly affected themselves.

The Advocacy Act enshrined the rights of vulnerable people. The commission made sure that those rights could be enforced. For hundreds of thousands of people, it was the first time they could be assured of knowing their rights, of making their wishes clear, of seeing a range of choices, even of arriving at their own decisions.

This new-found power raised issues around health care, employment, housing, transportation, education, social services. It provoked questions about medication, therapy, medical interventions, institutionalization. It brought to light environments of isolation, abandonment, neglect, abuse, unfortunately even violence. It confronted and challenged situations of control, power, hierarchy, harassment and intrusiveness.

They were never abstract notions to vulnerable people. But suddenly they had someone they could talk to, complain to, ask questions of, make decisions with. Suddenly they were offered some measures of protection, entitlement, self-respect, dignity and of course independence.

#### 1700

In the end, that's what advocacy is all about. As parents, families, workers, seniors and community members, many of us have acted as advocates ourselves and that will always continue. But when we can't be around, when we can't be there for our loved one, or when there isn't a loved one in sight, then we need to have advocates in place and a system of advocacy to make sure that vulnerable people have someone whom they can trust, who will be on their side, acting on their behalf, speaking out about their concerns, protecting them from abuse, helping them to get what they want and what they justly deserve.

The Advocacy Act and the Ontario Advocacy Commission were on their way to meeting those needs. They were there to ensure that their clients' legal and human rights were recognized and respected. They were there to assist clients in receiving the health care and social services to which they were entitled. They were there to help their clients lead lives that were as independent and productive as possible. They were there to protect disadvantaged people from financial, physical and psychological abuse. They were there to promote respect for the rights, freedoms and dignity of the vulnerable. My partner will take over.

**Ms Egan:** That's why we urge this government to step back and take a second, more informed look at the Advocacy Act and the work of the commission. In its short life, the Ontario Advocacy Commission consulted widely across the province with consumers, service providers, family groups, representatives from health and long-term-care institutions, and staff from correctional facilities. It set up a system to deliver rights advice, individual advocacy, systemic advocacy, public education and community development. It promoted the role and training of volunteers and professional advocates. It managed to write and distribute a wide range of materials about the act and the future plans of the commission.

That kind of work, the experience and knowledge gained, cannot and should not be stopped even though the



repeal of the Advocacy Act may slow its progress. We call upon this government to accept the recommendation from the Ontario Advocacy Commission to establish a barebones, non-profit corporation which would focus on community development, public education, training and systemic advocacy. It is far less than what is required, but as a replacement for the commission it is the very least that a caring government in a civilized society owes its most vulnerable citizens.

**Mr Marchese:** We thank you for your submission. My view is that it's a very thoughtful presentation of the situation that vulnerable people face and what the responsibilities of governments are. You make the case, as I do, that governments have a responsibility for advocacy. The government doesn't believe that government should be involved in the field itself. They believe in supporting organizations doing that; I'm not sure how. But this is the fundamental difference: We believe that governments need to be involved. The Advocacy Act gave people a voice. The commission gave people a voice, a coordinating voice in all of the areas that you mentioned around community development, training, education and dealing with systemic problems, because it recognized the reality that there is abuse out there. Not everybody's committing it, but many are, and we need a system whereby governments have some authority, through the Advocacy Act and the commission, to be able to get to it.

Your suggestion is that we establish a barebones, non-profit corporation which will focus on those very issues. My sense is that this is a reasonable thing to request. Mr Reville said that would cost approximately \$3 million. It's much less than the original \$18 million that had been proposed for it, but it would again be the focus of what people have asked for for so many years. I agree with you that taking it away would be a problem.

I want to agree with the argument you made that sometimes we forget the causes that make people very vulnerable. When we as governments reduce the social assistance that we give to them, it makes them even more vulnerable. I think you make the case that it's as a result of this that more than ever we need advocacy, for the governments to have it. To take it away impoverishes those vulnerable people even more. We thank you for your comments in this regard and we hope that the government will listen, at least, to those modest compromises that you're proposing.

**Mrs Boyd:** I'm going to thank you as well. I think one of the things that you both probably know, as people who have done work with the union and with collective bargaining, is that one of the issues around the imbalance of power that happens in that forum is very similar to the issue of imbalance of power between the medical profession or health care providers in general or facility operators and the individual who's there, and that's lack of information, the inability to actually get full information and to be able to know what is going on.

When you say you would agree with the barebones kind of non-profit group that's suggested by the Advocacy Commission, would you see that as being effective only if there were legislative right of access to the individuals and also access to the information that you require in order to advocate on their behalf?

**Ms Egan:** Yes.

**Mrs Boyd:** Because that's one of the major issues that we've seen. I want to thank you for giving us the cumulative catalogue of what has happened to disabled people in this province over the last few months, because it is the cumulative effect of everything that has happened that is so discouraging for those vulnerable people, and we haven't had quite as clear a list of all the various things that have affected them adversely as you've given.

**Mr McNeil:** The abuse to the elderly is terribly on the increase here in Ontario, as you probably all are well aware. One of the very sad things about it, of course, is the increase of the women of the family who are leading the way in abuse and many other things.

I'm sure you're all aware of what happens in the United States. Every month in the United States one senior in every state, at least one senior in every state, is found abandoned on the road or somewhere, just left by the family because there's no one to fight for them and the family can't look after them. From what I've seen happening in the last year, the last months at least, I don't think we're too far away from that here in Ontario, unfortunately. Unless we get an advocacy set up that will take care of that, I don't know what's going to happen.

As I mentioned in the report, I was responsible for putting that conference on. I invited a lawyer and I invited a minister from the government, thinking I'd have a great confrontation and there'd be a great free-for-all and all of the participants would be able to really shower a lot of questions on them. It was a small group; there were 68 people there. There was no confrontation, no argument. The lawyer had to admit that it was probably one of the best programs this province had ever seen. The only thing the lawyer happened to say to me—and understandably, being the lawyer—was that there should maybe be some more money for the legal aid system.

**Mr Ron Johnson:** I want to thank both of you for your presentation. I want to say at the outset, and I've said it many times before, that this government by no means has given up on advocacy; in fact, we support it. What we differ with of course is the approach. I think it's important to recognize that all we have said no to at this point is this \$18-million bureaucratic boondoggle of the previous government. That's all we've said no to. We support advocacy.

I want to make a couple of points. We believe that the current Advocacy Act is confrontational. It's adversarial. It doesn't really promote in our view the kind of family, the kind of friendship, the kind of existing organizations that are out there in terms of providing advocacy. Any time you get a big bureaucracy involved, you take away quite frankly from the direct, grass-roots kind of service that I think we all want to encourage in government.

**1710**

I want to add too that you mentioned the commission's report and I want to suggest to you that we are looking at that. We're looking very closely at it. It's one of a number of ideas and suggestions that we've had during these hearings that we're going to look very closely at in terms of coming up with a concrete plan for advocacy that will really meet the needs of the vulnerable through the kind of support systems we'd like to put in place. We



talked about training as part of the government's role. We talked about support mechanisms as part of the government's role. So I just want to highlight that to begin with and I want to say that we're not the only ones who have said that. Even my friend, my Liberal colleague Ms Caplan, on November 27, said that the current structure of the Advocacy Act was confrontational and adversarial; she agreed with that as well. So it's a widely held view.

A couple of points I just want to quickly clarify if I can: You indicated within your presentation—and I'm concerned because there are in my opinion some inaccuracies here—"The medical professions...will no longer have to be concerned about having to defend their decisions in the face of well-informed review." I would suggest that's incorrect. There is the College of Physicians and Surgeons, which carefully monitors doctors' performance in terms of direct patient care.

As well, you said, "Families who are prepared to make choices in their interests rather than in the interests of their vulnerable relatives." Again, there's a mechanism in place within the legislation, section 35, that's very clear in saying that if a substitute decision-maker is making a decision on behalf of their family member and it's not in the best interests of that patient, the doctor can appeal that. So it's important to recognize that there are safeguards put in place to ensure that the patient is always looked after and that the vulnerable person's wishes are always first and foremost.

**Mr McNeil:** But that's not really true. As a person so involved with seniors, I come across it all the time; it's happening every day. There's a family member somewhere taking advantage of someone, including talking them into handing over all of their rights, bank accounts and the whole thing. I don't believe the legislation is there. I would like to believe that the doctors are very honest and helpful, but the complaint has to come to them. What we're saying is, that's not happening. The vulnerable person is in the position where they're very scared to make complaints to anybody, let alone to a doctor. That's where we see the need for the advocacy system. I wish I had the packages that the previous government put out to give to you, you know. Like I said, I gave it to seniors all around. I never got a complaint from them. I have two personal friends who died in the last five years. I know the family was taking advantage of them and I tried to do something about it, but I couldn't. I wish there had been a good advocacy system in place then for those two people.

**Ms Egan:** If I may just add this addendum, I think the point really is that rights and caring have to be ensured. What we're saying is, what existed prior to this wasn't ensured. The Advocacy Commission and the Advocacy Act were not simply the result of the NDP policy. They were the result of years and years of problems highlighted through coroners' reports, through submissions made by seniors' organizations, through health care organizations and those who were involved in advocating. No commission, no act is perfect, obviously, but we have a tremendous fear that if it is not enshrined in legislation, if there is not a way to protect what are the rights of all people in Ontario, then there's going to be abuse.

That's what we're here to suggest you take a very strong look at, if not the first, then the proposal that we

put forward at the end, which is much more cost-effective perhaps and is not perfect. We feel people will be sentenced to very, very hard times in this province—it's the lean, mean decade anyway—and this is one thing that will make sure that people are at least treated with dignity and respect, particularly in their elderly years. We're very fearful, particularly from the experience of our older members, that it's not taking place. So we'll leave it at that.

**Mr Ramsay:** Thank you very much for your presentation. You've done a very, very good job. When you look at, as my colleague has said, your cataloguing of the cuts of this government, you would have to conclude, as you have concluded, that this government is targeting vulnerable people. I don't see these cuts as targeting the rich and famous in Ontario at all, but targeting vulnerable people, and through those cuts I'm sure they are going to create more vulnerability in this province. It's shocking when you see it all together, as you have listed it, where those cuts are.

I just want to tell you that in the Liberal caucus we do believe in a revamped system. From what we've seen so far, we like very much the \$3-million proposal that the commission has put forward, albeit it is a barebones proposal, but I think it looks sound and we are certainly encouraging the government to pursue that.

We think it's very important that the government pursue that using the principles of coordinating advocacy in this province, and maybe it should be looking at a regional model for that. Quality standards would be another principle that we would impress upon the government to be using with its model. We think training is very important for the people, whether they be volunteers or paid staff, that they be properly trained and, in the end, accountability, so that we as taxpayers and legislators can have confidence that the people are doing the job that the vulnerable people in Ontario deserve. Again, thank you very much.

**The Chair:** Thank you, Ms Egan and Mr McNeil, for your most interesting presentation.

PETER LILICO

**The Chair:** Last but not least, Mr Lillico. You have the written submission and Mr Lillico has agreed he has 10 minutes.

**Mr Peter Lillico:** And I will keep it to 10 minutes.

I'm not speaking on behalf of any constituency. I'm a lawyer in Peterborough. I have a client base which is largely—not largely but at least half—senior citizens. I have knowledge that I have built up over the last year since the Substitute Decisions Act was passed, based upon dealing with hundreds of personal care powers of attorney and powers of attorney for property with my clients and also by giving seminars. I don't pretend to have special expert knowledge.

I'm not speaking on behalf of the most vulnerable people as many of the previous presenters have. I'm speaking on behalf of my clients, who are capable people who wish to put in personal care safety systems or property safety systems in the event that they ever become incapable or vulnerable in that way. In so doing, I have noticed over the last 11 months or so a number of



practical problems that have arisen that have prevented the implementation or made more costly or ineffective the implementation of some of the laudable goals of substitute decision-making. I will very briefly review those.

The most important one that I put at the top of my list is preferred assessors. I have just had the advantage of speaking to Trudy Spinks and it may be that my concern here has already been addressed. There is, as you know, under the Substitute Decisions Act a requirement that an assessor be a trained and qualified person. I have many clients who feel far more confident in naming a family member, a friend, somebody they know, who has a better idea as to their capabilities than any assessor, no matter how well trained, can form in a matter of hours.

I should also say as a matter of philosophy—and I will be speaking practicalities, not philosophy—the hundreds of ordinary people that I speak to trust their friends, their family and their doctors far more than they trust the government, the courts or, I'm sorry to say, the lawyers. That is where I am coming from, and it's obviously a different perspective from many of the people who have been before you previously.

My concern with the preferred assessors previously was that it restricted it to a class of people who were not—there was no point in saying, "I want this person to be my preferred assessor." It was simply one of several people, only two or three in Peterborough county, who had been approved to be assessors. There may well be the opportunity under the new legislation for them to provide a method of confirming which will permit them to name their own assessors. I did not read it that way and I discussed it with Trudy Spinks, and she tells me the intention is different. This is 49(1), (2) and (3). The only recommendation I would make there would be to say, please let people choose who it is that will be confirming their capacity or lack of capacity.

It does say that they may choose their method; it might be clearer if it was restated to say "the method and the person who is determining." I read it to mean that it still needed to involve an assessor who was a qualified person, but the method was that the assessor was directed to speak to various people or do various things. That is the most important single point that I would like to make and the one that would most please my clients.

1720

Second is the prohibition of doctors as attorneys for personal care. There's a logical reason to keep out people who provide care for compensation, but I do not believe that applies to doctors. I've given an example in my written material of one person, who is not unusual at all, who trusts her doctor and would like her doctor to be her personal care power of attorney. The doctor would agree to do so, although it is obviously an unusual situation. She can't do it and she's a very unhappy lady because of that. There are many more in that situation. I think that the general rationale, which I do agree with, of excluding paid care providers does not really apply to doctors, who don't really have much of a financial self-interest in personal care matters.

Termination of power of attorney: Now this is the property power of attorney. Many of my clients are aghast to discover that they have done a general continu-

ing power of attorney for property which is strictly to come into effect if, but only if, they lose capacity, and we do specify how that lack of capacity is to be determined. They do that as a safety net for themselves, and then a year or two later may, for other reasons, do a limited power of attorney at a bank for convenience and then perhaps find that they have terminated the general power of attorney, which was never their intention, and they feel that they have protection and they have lost the protection. I believe that a very small legislative change that simply says, "A general continuing power of attorney for property is only terminated by another general continuing power of attorney for property," would be a most appropriate and safe measure.

Another point I had I believe is already addressed by subsection 8(2) of Bill 19, which terminated the power of attorney for property's authority if the public guardian and trustee became involved. I believe that has been addressed by 8(2). I'm a firm believer that, if somebody names somebody to be their power of attorney for property and trusts them, that should not be terminated simply by an administrative function, notwithstanding the fact that it may be relatively simple to reinstate them.

I can tell you as a matter of practice that there are unexpected glitches and time concerns that can arise in that period of time, and I can give you an example, if called upon, where that costs thousands of dollars to a client whose resource stocks were dropping in the interim period between the time that the attorney for property lost authority and regained it under the process.

Lastly, posting security: I am right now dealing with a client who is in the Belleville area. He had appointed his only son, who happens to be working in the United States and is a resident now of North Carolina, as his general continuing attorney. That was terminated by the father's certification of incapacity.

The son then applied through the process to become appointed as the statutory guardian of property in order to continue with father's real estate deals etc and ran into the security problem, which is that there is no discretion under the Substitute Decisions Act for the public guardian and trustee to dispense with the need to post security. That left this family with either a \$650 security bond or the alternative of going to court to dispense with the necessity for posting security, neither of which was very attractive. I suggest in the circumstances neither was required when the father, while competent, had already made his decision that this son, regardless of where the son happened to be residing, was the one that he wished to act.

My recommendation there I believe is partly addressed by Bill 19, which does not require the posting of security unless the public guardian and trustee specifically demands it, which is certainly an improvement. I suggest it would be further improved by a provision that the grantor could specifically exclude the opportunity for the public guardian and trustee to make such a demand—in other words, let the person decide themselves who they trust—and put the public guardian and trustee in the situation where, if for whatever good and valid reasons they feel that an error has been made, the public guardian

and trustee has the onus of applying to court to reinstate the bond. That's eight minutes.

**Mr Parker:** Mr Chairman, what I was going to suggest is that given the nature of this presentation, which deals with some of the technicalities of the draftsmanship, I was prepared to invite Trudy to respond to some of the points that were made. I'm happy for her to use my time to do that or to do it in private with the deponent at another time.

**Mr Lillico:** I've dealt with Trudy several times. I'll be happy to talk to her on our own time.

**Mr Marchese:** He was recommending we use a few moments to allow—

**Mr Lillico:** I'm easy.

**Mr Marchese:** That would be fine with us too.

**The Chair:** Okay. We have four minutes, Ms Spinks.

**Mr Marchese:** Unless you are unable to because of the cold, which we'll understand. I forgot about her cold.

**Ms Trudy Spinks:** I really don't have a rebuttal particularly. Some points of view have been raised and the committee might want to consider whether they, the committee members, feel some of the points that are raised are ones that should be taken into consideration.

These things always have a pro and a con, and I guess some of the issues that we did think about when we were drafting have been raised, particularly with respect to the issue of powers of attorney that are terminated by a later power of attorney. That's one where we've had a lot of discussion about the merits of the existing section.

I think Mr Lillico's point is a good one, that it's true people often do make a limited power of attorney for banking purposes, for example, or with a business arrangement, forgetting that they made a general power of attorney as part of their estate plans and inadvertently revoked the earlier general power of attorney.

However, the reason the legislation is as it is now, which says that you can say otherwise when you make the later one that, "No, I want to preserve any existing ones," and if you don't say that then the earlier one automatically falls, is to prevent what we call a pile up of powers of attorney that exist over the same asset because people forget, and then when there's incapacity there are three people standing at the bank wicket fighting over the same asset.

That's the rationale, and if that were changed in the way that's been recommended by Mr Lillico—and I think you may hear that from other presenters as well—he's got a very good point, but that issue that I mention in terms of the multiple powers of attorney accumulating is the reason it is the way it is. So one has to weigh those two issues, but I guess that's why we're here.

**Mr Marchese:** What about a response about preferred assessors. He was saying that the way he read it, it talked about the wording of the method as somehow implying that the person, through that wording, would be able to state a preference, and I read it the way he does. Is that the case, or is there some flexibility with the wording with respect to interpreting?

**Ms Spinks:** That wording was taken from the wording that's in the existing act for powers of attorney for property, if you look at that part that has remained unchanged. Certainly that section of the legislation, as it pertains to property, has always been construed to include—for example, the most typical method is a letter from my family physician that says I'm incapable. That, to me, brings in the idea of the preferred assessor. Basically you're saying who it is who's going to provide the evidence of your incapacity, and we've always read that section that way. That's why it was written that way for personal care. If the committee feels it's not clear enough, then perhaps they want to recommend that it be clarified.

**The Chair:** Thank you, Ms Spinks.

**Mr Lillico:** If I could make one comment there, please.

**The Chair:** It will be your last.

**Mr Lillico:** Yes, it will be. It's just simply that people may wish to not use their doctor. I have no problem with what Trudy is saying, but some people want to use their sister, they want to use their brother, they want to use their children. It would be much better if it was clear that they had the ability to name their own confirmers.

**The Chair:** Thank you, Mr Lillico, for coming from Peterborough. Have a safe journey home. Unless there's some other matter, this hearing is adjourned to 9 am, February 20, room 1.

*The committee adjourned at 1731.*



## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

**Chair / Président:** Martiniuk, Gerry (Cambridge PC)

**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

\*Boyd, Marion (London Centre / -Centre ND)

Chiarelli, Robert (Ottawa West / -Ouest L)

Conway, Sean G. (Renfrew North / -Nord L)

\*Doyle, Ed (Wentworth East / -Est PC)

\*Guzzo, Garry J. (Ottawa-Rideau PC)

Hampton, Howard (Rainy River ND)

Hudak, Tim (Niagara South / -Sud PC)

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\*Klees, Frank (York-Mackenzie PC)

\*Leadston, Gary L. (Kitchener-Wilmot PC)

\*Martiniuk, Gerry (Cambridge PC)

\*Parker, John L. (York East / -Est PC)

\*Ramsay, David (Timiskaming L)

Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Caplan, Elinor (Orléans L) for Mr Conway

Kells, Morley (Etobicoke-Lakeshore PC) for Mr Tilson

Brown, Michael A. (Algoma-Manitoulin L) for Mr Chiarelli

Johns, Helen (Huron PC) for Mr Hudak

Marchese, Rosario (Fort York ND) for Mr Hampton

### **Also taking part / Autres participants et participantes:**

Ministry of the Attorney General

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## Legislative Assembly of Ontario

First Session, 36th Parliament

## Assemblée législative de l'Ontario

Première session, 36<sup>e</sup> législature

# Official Report of Debates (Hansard)

Tuesday 20 February 1996

# Journal des débats (Hansard)

Mardi 20 février 1996

## Standing committee on administration of justice

## Comité permanent de l'administration de la justice

Advocacy, Consent  
and Substitute Decisions  
Statute Law Amendment Act, 1995

Loi de 1995 modifiant des lois  
en ce qui concerne l'intervention,  
le consentement et la prise  
de décisions au nom d'autrui

Chair: Gerry Martiniuk  
Clerk: Donna Bryce

Président : Gerry Martiniuk  
Greffière : Donna Bryce



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## LEGISLATIVE ASSEMBLY OF ONTARIO

STANDING COMMITTEE ON  
ADMINISTRATION OF JUSTICE

Tuesday 20 February 1996

## ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

COMITÉ PERMANENT DE  
L'ADMINISTRATION DE LA JUSTICE

Mardi 20 février 1996

*The committee met at 0904 in committee room 1.*ADVOCACY, CONSENT  
AND SUBSTITUTE DECISIONS  
STATUTE LAW AMENDMENT ACT, 1995  
LOI DE 1995 MODIFIANT DES LOIS  
EN CE QUI CONCERNE L'INTERVENTION,  
LE CONSENTEMENT ET LA PRISE  
DE DÉCISIONS AU NOM D'AUTRUI

Consideration of Bill 19, An Act to repeal the Advocacy Act, 1992, revise the Consent to Treatment Act, 1992, amend the Substitute Decisions Act, 1992 and amend other Acts in respect of related matters / Projet de loi 19, Loi abrogeant la Loi de 1992 sur l'intervention, révisant la Loi de 1992 sur le consentement au traitement, modifiant la Loi de 1992 sur la prise de décisions au nom d'autrui et modifiant d'autres lois en ce qui concerne des questions connexes.

BEN CLEMENS  
SHEILA CLEMENS

**The Chair (Mr Gerry Martiniuk):** Good morning, members, ladies and gentlemen. Our first submission is from Mr Ben Clemens and Mrs Sheila Clemens. Thank you for attending. I know I speak on behalf of the whole committee in extending condolences to you about Lonnie, your son. You have one half-hour and you may proceed at your convenience.

**Mr Ben Clemens:** I come to this committee today with no credentials nor professional expertise, but simply as a bereaved father devastated by the recent loss of my 28-year-old developmentally challenged son, Lonnie, just 10 months ago.

He met his tragic death only four and one-half days after entering Sunnybrook Health Science Centre suffering from an impacted bowel. Due to his constant refusal to give informed consent to treatment because he was so frightened, despite our pleas for physicians to treat him, especially since a psychiatric assessment had been done one and a half years prior when he was in a similar condition and he was found to be incapable of understanding the consequences of refusing treatment and acting in his best interests, following his admission, he lay in bed for three days before physicians finally gave in to our insistence that treatment commence. By that time, it was too late to cure a desperately ill young man.

It is quite apparent that the staff, in general, had an incomplete understanding of the Consent to Treatment Act, which delayed initiation of treatment. They were clearly intimidated by the legislation.

I shall not expound on the events which led to his untimely death and the circumstances which we, his immediate family, and Lonnie were subjected to at the hospital, as you are undoubtedly well aware of this tragedy by now, as well as being aware of the recently concluded coroner's inquest into Lonnie's death. I shall deal later with my comments in support of specific recommendations which came as a result of the inquest and which will be reflected in situations encountered at the hospital centring on the Consent to Treatment Act.

Firstly, it is necessary to profile this special young man which respect to his strengths and weaknesses in order to deal with the subject of capacity which appears, for all intent and purpose, to have been the basis upon which the Consent to Treatment Act was legislated by our former government and shall continue to be of primary concern in the Health Care Consent Act.

To his family, friends and acquaintances, Lonnie was remarkable. He loved people, carried everyone's problems on his young shoulders, and was caring, concerned and thoughtful. He was indeed a decent human being.

Life, though, was not easy for Lonnie. Besides possessing growth problems for most of his early years, he was developmentally delayed and plagued with behavioral outbursts due to his frustrations, and as a result faced many obstacles and difficulties throughout his 28 years. Yet, in spite of them, he became an asset and well-respected member of the special-needs community. Lonnie viewed life as an adventure and a challenge. He faced each day with optimism, trying his utmost to please himself as well as his family.

He spent all of his leisure teen years, up to the day he died, at the Bathurst Jewish Centre, taking part in special-needs groups led by qualified instructors and educators. He volunteered for many of those years leading, inspiring and motivating those less fortunate than himself. This affable young man was a mentor to his special-needs peers who constantly looked to him for encouragement and motivation.

In June of 1992, Lonnie was chosen to be honoured by the JCC at their annual sports celebrity banquet for his many years of service in his volunteer field. That evening, his proud family celebrated with him as he was honoured by Bruce McNall, the late John Candy and Wayne Gretzky (in absentia), while his trophy was presented to him by Eric Lindros.

In order for you to put into perspective the type of individual Lonnie was, and how he presented himself as the epitome of strength and self-assurance etc, I ask you to watch the following brief video presentation where you can watch this young man ad lib his way through the

description of the value and importance of the special-needs department at the Bathurst Jewish Centre.

*Video presentation.*

0910

**Mr Clemens:** That's just a glimpse of Lonnie the way he was. We just thought we should show it.

As Lonnie approached 25 years of age, my wife and I realized that we must plan for this young man's future while we were still alive, to ensure that he would have a home and responsible people to provide the support he would require in a suitable setting.

Having selected Reena as the agency with a philosophy in which we believed, Lonnie moved into an apartment shared by two other men in October 1991, where he remained until August 1992, when he moved into a less structured, semi-independent living environment, a two bedroom apartment. With the assistance of the counsellor to assist with banking, shopping and other areas requiring guidance, Lonnie and Stuart set up house and a new life for both of them.

Lonnie was also capable of holding down a four-and-a-half-hour, five-day-a-week job at McDonald's. This opportunity was afforded him by an employer who was both stern and kind, expecting him to adhere to rules and regulations. Just six weeks before he died, a surprise party was held for him celebrating eight years of loyal service. He made a touching speech thanking his McDonald's family for their patience and guidance through the years, pledging to continue for many years.

Thus far, you see a young man possessing incredible strengths, but there was, however, another side to Lonnie—his weaknesses. These included phobias, fears—especially of doctors—anxieties, psychological hangups, inability to comprehend time, and most of all, his inability to cope with illness and to understand his body.

At this point, it is appropriate to attempt to define the term "developmentally challenged" and to make you aware of the many degrees of difficulties and limitations which are prevalent in this population depending upon the situation they face.

The term "developmentally challenged" describes a complexity of behaviours combined with different degrees of intellectual impairment, as well as emotional and social dysfunction. It is unfair and impossible to place developmentally challenged individuals into one category with respect to their capability to understand and appreciate consequences when faced with major decision-making.

Considering that many developmentally challenged are non-verbal, have any provisions been made in the new legislation which would suggest a practice to follow to ensure that proposed treatment, especially in emergency or urgent situations, be expediently carried through without the prerequisite of calling and awaiting a rights adviser? In many cases, when a developmentally challenged individual enters a hospital, even though they may appear capable of understanding a proposed treatment, it is essential that medical personnel listen to family and/or primary caregivers who can provide essential information about the patient.

It is therefore extremely important for health caregivers to have an awareness, recognition and possess education with respect to the developmentally handicapped. In

Lonnie's case, he was capable of making minor decisions relating to issues excluding health care, with guidance and assistance of his family and social worker. However, when faced with any matters or decisions relating to health care, especially hospitalization, and fears brought about with respect to treatment, he would regress to a small child, act inappropriately and be unable to understand and appreciate treatment being offered to him. The aforementioned was his demise.

The following portion of my presentation will deal with various recommendations stemming from the recent inquest revolving around the circumstances and events contributing to Lonnie's death which are relevant and apply either directly or indirectly to certain aspects of the HCCA, especially with respect to the developmentally challenged community.

Recognizing capacity or incapacity has become a prime concern and must be dealt with adequately and carefully in the new Health Care Consent Act.

Listed as two of eight definitions of "capacity" taken from Webster's New World Dictionary are, "(a) the ability to contain, absorb, or receive and hold; and (b) the power of receiving and holding knowledge, impressions etc; mental ability."

With respect to the developmentally/intellectually challenged, it is imperative that a clause be inserted in the informed consent subsection 10(2), part II, stating, "a person is able to understand the information about the proposed treatment, appreciate the consequences of having or refusing treatment or of making no decisions, and is capable of explaining in his or her own words what the health practitioner has set out."

Considering the determining capacity of the developmentally challenged can become an extremely complex procedure and the consent legislation should be amended to allow health caregivers to delegate capacity assessments when they are beyond their expertise in this regard.

Recommendation 11: It is recommended that the proposed legislation define "capacity."

Recommendation 15: It is recommended that substantive issues such as the determination of capacity and the exceptions to the definition of treatment in the HCCA be set out in the body of the legislation and not embodied in the regulations.

Recommendation 29: It is recommended that in any new legislation, special care must be taken to define in a comprehensive and clear way the following: What are the situations in which capacity must be assessed?

Recommendation 29: It is recommended that in any new legislation, special care must be taken to define in a comprehensive and clear way the following: What is an emergency?

One proposal to achieve these goals would be to define an emergency in terms of a person who is apparently experiencing significant pain or ongoing discomfort or is at risk of sustaining bodily harm.

Health caregivers must be capable of recognizing when an emergency exists, thereby treating patients in a timely fashion, as well as immediately addressing the subject of incapacity if the occasion arises.

Delays in patient care: In the May 1995 issue of the College of Physicians and Surgeons' Members Dialogue,



only three weeks having elapsed since the proclamation of the Consent to Treatment, Substitute Decisions and Advocacy Acts, Dr Walker explained the reservations the college had about many aspects of the acts and the fact that they, the college, were besieged by doctors expressing frustration and concern about the serious difficulties they were having providing care to some of their patients. Specifically, the college had become aware of a number of cases in which necessary medical care had been inappropriately delayed by virtue of physicians and other health care professionals complying with the legislation, which had proven to be unnecessarily cumbersome and complex.

Dr Walker went on to say that, ironically and tragically, the most seriously disadvantaged members of our society, ie, those vulnerable individuals whose interests were to have been protected by the legislation, in fact had borne the brunt of its negative effects: specifically, elderly persons and developmentally challenged adults living in the community semi-independently.

0920

**Recommendation 9:** It is recommended that a clause setting out the statement of purpose should be put into the HCCA to explain that the act has a dual purpose, that being the preservation of patients' rights and to facilitate timely treatment for persons incapable of giving consent.

**Recommendation 12:** It is recommended that the one-week appeal period set out in the Consent to Treatment Act following the Consent and Capacity Review Board's confirmation of incapacity be eliminated to permit immediate treatment.

**Substitute decision-makers:** My wife and I support the fact that people's rights must be protected and wishes honoured, especially with respect to the developmentally challenged, as long as they are capable of understanding and appreciating the consequences. At the point, however, when a developmentally challenged individual is incapable of making those decisions and has been assessed as incapable, supportive family and friends should be the primary substitute decision-makers.

**Recommendation 22:** It is recommended that any changes to the health care consent legislation retain the following principles: the respect for the right of an individual to make their own decisions to the greatest extent possible; the supportive family and friends should be the primary substitute decision-makers where this is necessary.

**Plain language:** Judging by health caregivers' uncertainties about the Consent to Treatment Act and the lack of adequate preparation and training about the legislation, it should be in everyone's best interest for Bill 19 to include the following: All rules and regulations should be in simple language to facilitate comprehension and minimize difficulties in interpretation.

**Recommendation 6:** It is recommended that in drafting new legislation, there should be a genuine attempt to use plain language.

**Education of health caregivers:** Despite the tragic loss of our son, my wife and I have committed ourselves to joining forces with Reena on a task force in an attempt to find ways to educate health caregivers about the developmentally handicapped, recognize difficulties they possess

and how to deal and communicate with their families and primary caregivers. The government should adequately prepare health caregivers and health facilities with sufficient information and time to be knowledgeable in all facets of the legislation.

**Recommendation 8:** It is recommended that adequate funding should be made available to assist affected health care practitioners with education and training for the HCCA, the proposed new legislation, especially before it is implemented.

**Recommendation 20:** It is recommended that health practitioners coming into this province from other jurisdictions should be required to be trained immediately in the assessment of capacity and the Health Care Consent Act.

Your undertaking in the rewriting of this complex legislation ensuring that no further tragic deaths occur as a result of it could be Lonnie's legacy.

I thank you for the opportunity to address this committee. Respectfully submitted, Ben Clemens.

**Mrs Elinor Caplan (Oriole):** It's nice to see you again, Mr Clemens. It's important that you appear before this committee and share your experiences. As you know, I've been very concerned about what the impact of this legislation might be. I have a copy of the findings of the inquest. If they have not been tabled with the committee, I will do that, and I hope that the government will in fact draft amendments to implement all the suggestions that have come out of the inquest.

You've raised one that would take a little time, but I hope they will do it and I just wanted to go on the record as saying we would support that, and that is rewriting the legislation in plain language. It is important to do that so that people, both caregivers and families and anyone who has an interest in knowing both what their rights are and also what they can expect, can understand it. When you read this legislation, particularly the referrals to other sections of past legislation, it's very complicated. I don't know if you want to say anything further on the need for plain language.

**Mr Clemens:** I think it's very important that people really understand what they're reading. The past act—or it's still the present act until it is changed—you really had to decipher every word to get to know what it meant and even lawyers had problems, so you could imagine the problems that the medical staff had.

Incidentally, in everyone's brief there is a copy of the recommendations from the hearing.

**Mrs Caplan:** If you look at the legislation that's before us, I think there are many places within that legislation where the language could, and should, be simplified. That wouldn't change the content or the meaning of the legislation, and we would support that prior to third reading and would give our approval now that if the government did that, we would not delay the process in any way, because it is extremely important that you have legislation that people can read.

You've also addressed the issues of the need for education and training. I think that's key because the existing legislation that's before us, the new acts, does not give a mandate to anyone for the purposes of education and training under the legislation. While I think the

government has a role, I also think there are bodies perhaps that could do it better, whether it's the Consent and Capacity Board, the PPAO, Psychiatric Patient Advocate Office, as well as I think organizations such as Reena and others in a partnership, that could be very effective in making sure that that message is taken out. I wondered if you had a view as to whether it should be only government or whether we should involve as many people as possible.

**Mr Clemens:** It should definitely involve as many people as possible. In fact, one of the things that came out at the hearing, as I mentioned in this brief, is that in the medical establishment, doctors come from all over. They spend six months in this place, six months in another place, and especially those coming in from out of province really had no idea, number one, that there was such an act as the Consent to Treatment Act, and when they finally found out, they didn't understand it; they didn't know what it means.

It was also suggested that even in the medical school it can't do any harm to teach upcoming doctors that there is an act and what the act consists of and how to understand it, and especially how to assess capacity.

Doctors were taking it upon themselves, whether they knew how or they didn't know how, to assess capacity. Lonnie, for example, I call him a yes man. Whatever question you asked him, everything was yes. If you had given him Einstein's theory of relativity and asked him if he understood it, he would say yes.

Doctors have to be trained how to properly assess capacity. They cannot go in on their own assumption, because they ask a person, they pick up a thermometer and say, "Do you know what this is," and they say, "A thermometer." "Oh, he's got capacity."

**Mrs Marion Boyd (London Centre):** Thank you very much for coming. I know how difficult it is. I should say to you that obviously the intention of the existing legislation was as you state. The intention always was to make sure that people did give informed consent but also to do timely treatment, and it's very unfortunate that your tragic circumstances have served to show us that we didn't accomplish that in that legislation. So I really appreciate that you're trying to help us to come to the resolution of some of those problems.

I personally think your addition around informed consent that you have on your page 6 is excellent. I would suggest that we probably need, in the last line of that, to be talking about, "and is capable of explaining in his or her own words, or in whatever means of communication the person uses."

**Mr Clemens:** Correct.

**Mrs Boyd:** I think you would agree with that because what the health practitioner has set out: I think that would be the test, wouldn't it, so that people couldn't glibly answer yes or no and they would have to show that they really appreciated that. I think that would help everybody.

**Mr Clemens:** Definitely.

**Mrs Boyd:** I agree with your concern around the definition of an emergency, and I see it from both sides. I see that in your case, the kind of problem that you were facing wasn't defined as an emergency, although many of us, in talking about this situation, have said we don't understand why not. So I think some addition to that is

necessary. But I think often from a patient's point of view, we have to be sure that "emergency" isn't used to cover situations where in fact it isn't an emergency. So it's a kind of double-edged sword.

**0930**

On this plain language thing, I'm not sure it's ever possible to make legislation completely comprehensible to people, but I think the obligation of the government, particularly given the difficulties we've heard people come in front of us with in terms of understanding this, is to have some kind of a plain language explanation of exactly what is implied by each of the sections. It would be very helpful. We did that with the Substitute Decisions Act, but it wasn't done with the Consent to Treatment Act, and I think that created some real difficulties.

Rather than trying, because it's incremental legislation, to make that into the kind of comprehensive thing you're talking about, because I don't think that's going to happen in a timely fashion, making sure there's a plain language guide to it that's going to be useful to both patients and health care professionals, so we're all using the same words and the same definitions and we all have the same information we're working on, would probably be the helpful line. We know that lawyer's language and doctor's language and laypeople's language are very different things. What we need to be doing is make sure that we're all using the same words to describe things. I think that's what you really want to accomplish.

**Mr Clemens:** Absolutely, yes.

**Mr Gary L. Leadston (Kitchener-Wilmot):** Good morning, Mr Clemens. Personally, I extend to you my deepest condolences on the loss of your son. Today, and I think during the whole process, you've displayed tremendous inner strength that we can all learn from.

I'm rather inquisitive in terms of the recommendations of the jury and in one point that's contained in your submission. It's number 25: "It is recommended that there must be adequate protections for vulnerable persons which allow them to challenge both the finding of the incapacity and the treatment decision. The extent of these protections should reflect the seriousness of the treatment and the scope of the substitute decision-maker's powers."

I'm interested in knowing your opinion in terms of what occurred. Is it your sense that ultimately the physician or a physician has to make a determination regardless of the legislation? Do you feel that the physician in that case should have followed the medical procedures to relieve your son's symptoms?

**Mr Clemens:** He certainly should have followed whatever medically had to be done, but if he wasn't sure what had to be done, as in this particular case, and never took it upon himself to inquire with somebody who's higher up to ask for any advice or any instructions—everything that the doctors did in this particular case was all assumption; they were assuming that this is what should be done, according to my estimation. I remember as a youngster everybody used to tell me, "Don't assume," and they used to spell it out why you shouldn't assume. This is what happened in this case. They ended up being just what the assume stands for.

**Mr Leadston:** On a second point, in terms of the obligation of the health practitioners, do you feel they



should have an obligation towards the patient or the person who has been found to be incapable, that they have a right to have that finding reviewed?

**Mr Clemens:** Yes, they should have that finding reviewed, definitely, but within a time limit, though, not seven days later, a week later.

**The Chair:** Mr Clemens and Mrs Clemens, I thank you for attending today and for your courage.

## JUSTICE FOR CHILDREN AND YOUTH

**The Chair:** The next submission is Justice for Children and Youth, Cheryl Milne, staff counsel.

**Ms Cheryl Milne:** I apologize to the committee for not having a written brief for you. Our time constraints didn't allow it. I'd be quite happy to summarize what I am going to say today and provide that later.

I'd like to just briefly introduce Justice for Children and Youth to the members who may not be aware of what we do. We're a legal clinic that is funded through the Ontario legal aid plan that represents young persons under the age of 18 in all areas of law that affect them. We do young offenders' work, but we also do a lot of work with respect to health care, children's mental health and that sort of thing.

We presented written briefs on the Consent to Treatment Act and many of the recommendations we made in those briefs are still true or recommendations we still endorse. If you want to review those briefs, they were submitted in 1992 to the standing committee on administration of justice at that point. I will review some of the recommendations, but that document is still relevant to the legislation we're looking at today.

Our organization also strongly endorses the recommendations and concerns that were expressed in the material filed by the Advocacy Centre for the Elderly. I won't repeat all those recommendations, but we can say that we strongly believe that many of those recommendations also affect young people.

What I would like to do is just focus on our major concerns with respect to the new legislation. Our first concern is with respect to the repeal of the Advocacy Act and the absence of provisions for rights advice to a person deemed incapable. It's our recommendation that someone must be required to communicate the finding of incapacity and the right to a review of that finding to an individual who has been deemed to be without capacity to make a decision.

Young persons are particularly vulnerable in this area. They are generally accepting of adult authority. The image of the omnipotent adolescent refusing necessary treatment, although it exists, is not representative of youth in general. Without the requirement that the young person's rights be communicated to them, we are going to just see young people's rights being run roughshod over. I think there's going to be a serious charter challenge to this legislation if there is not some mechanism for communication of the rights of that person when they're found to be incapable of making a decision around their own bodily integrity.

I was listening to the submissions of the previous people regarding plain language. I think that fits with the

obligation to provide rights advice or the communication of the person's rights at the time of finding of incapacity. I think the plain language applies in that area. The legislation the way it's written now just applies to the health care providers. You're not going to find a young person who's going to go and look up the act. You're not going to find very many people who are going to go look up the act to see what their rights are. They're going to be faced with a situation and told that there's a decision made, and at that point, without knowing that there's a piece of legislation that governs them, without knowing that they have a right to appeal the decision if they don't like what's happening, you can have all the plain language you want, but it's never going to be read.

Also inherent in the rights of the individual is the aspect of education and training. It's not just for the health care providers; it's for the people who are in the institutions who are going to be affected by the decisions made under this legislation. There should be a mechanism for training, certainly for the people involved in providing the health care, and again we submit that there has to be some kind of advocacy role within the legislation.

Without it, there is no real check on what the health care providers are doing, or, not necessarily assuming that they're going to make a bad decision, we have a whole list of substitute decision-makers who are going to be making decisions about these young people and about anybody under the legislation that there needs to be a check on as well.

## 0940

With respect to parts III and IV of the legislation, it currently, as worded, doesn't apply to persons under 18. It seems to be focused on the elderly. Our question is, will the definition of the care facilities be expanded to include residential settings for children? That's unclear.

If it does, and if that's going to happen, and obviously it would be done under the regulations, we share the concerns of the Advocacy Centre for the Elderly regarding the competence of evaluators in respect of the admissions procedures, also the concerns about the personal assistance plans regarding restraints and that sort of thing, because these are things that are used against young people quite often. We see restraints being used sometimes against the elderly for their own good, but we also see restraints being used against young people in residential settings all the time.

Right now, we don't have a clear set of guidelines around consent issues to the use of those restraints in respect of behaviour modification and that sort of thing for young people. At this point, it's unclear that the legislation will apply, but my concern is that we're going to see regulations that just include a whole host of children's residential settings without much input.

Another concern we have is the definition of "treatment." At this point, it excludes treatment that poses little or not risk of harm. In my view, that's much too broad in terms of an exclusion. We feel this could potentially include very intrusive procedures: for example, an internal gynaecological exam. That was one of the issues we brought up under the last Consent to Treatment Act in terms of the importance of allowing someone to be able to consent to those kinds of examinations. That's



just one example. I have serious concerns about how the definition of "little harm" or "little risk of harm" is going to be developed and who's going to be making that decision.

We also have concerns around the conflict of emergency treatment. Our concerns actually apply equally to the current Consent to Treatment Act in that a person under 16 is never able to control the treatment because their wishes while capable can be overridden. If you have a 15-year-old who has been deemed capable and has been guiding their own treatment up to a certain point, and then it reaches an emergency stage, and it may be part of an ongoing medical condition but it now reaches an emergency stage, and they have clearly expressed wishes not to undergo a specific type of treatment, those wishes can be overridden under the current legislation and under Bill 19, because those wishes do not govern.

It's our concern that if you are going to treat someone as being capable, why do you set an arbitrary age by which they're no longer capable or their wishes no longer matter, when they mattered all the way up to a certain point? The common example that's used is a young person who may have certain religious convictions that would preclude them from having a blood transfusion, for example. Another example might be a young cancer patient who is just tired of all the treatment and is maybe terminal and just doesn't want to go through any more procedures and has clearly understood the ramifications of refusing treatment.

With these kinds of emergency treatments, obviously, we're talking about the right to refuse treatment, because in fact that's what the real issue is with young people, their right to say no to certain kinds of treatment. That's the kind of issue that tends to get people really upset, when we see a young person who may be saying no to a treatment that other people think is in their best interests.

Another major concern we have is in respect of the makeup of the Consent and Capacity Board. It's our recommendation that it should remain a three-member panel, at least one member to have expertise in capacity issues. When youth are involved, then one member should have expertise with young persons, because we think that their issues are specific to them, and incapacity issues with young people are not the same as capacity issues for the elderly or for an adult.

Again, we reiterate the recommendations that the Advocacy Centre for the Elderly has made with respect to the procedural aspects of the hearing in terms of allowing the chair to establish certain uniform procedures, so that someone going before the panel knows what procedures they have to follow, so that there is some uniformity and some predictability about the process.

Another major concern for us is with respect to the conflict with the Child and Family Services Act. We sat on a panel under the Consent to Treatment Act to look at those areas of conflict. One thing that the process in developing this legislation has not provided is any consultation with the people who are working with young people in this area of the law.

The current bill allows for a one-year wait before the act takes precedence over the CFSA. That was the same provision that was under the Consent to Treatment Act.

Why do we need another year? It's my submission that the basic provisions of the Consent to Treatment Act have not been modified that greatly, except for the rights advice. I certainly see some improvements in Bill 19. There were some holes in the earlier legislation, but in terms of the right to make your own decision, that clearly has not been altered in terms of the basic principle. The mechanism for it and whether or not that's a right that's going to be exercisable has certainly been altered in Bill 19, by taking out the right to be informed of decisions made about you, but the basic principles are still there. So I don't see why we need to have yet another year where the CFSA would take precedence over the consent legislation.

There may be areas in which there's conflict. The only direct area of conflict is with respect to psychotropic drugs, and it's always been our submission that the consent-to-treatment legislation should be the governing legislation when it comes to medical treatment of children in care and that the CFSA is a process which doesn't really lend itself quite easily to the consent-to-medical-treatment issues that you see under the Health Care Consent Act or the Consent to Treatment Act. They are separate.

It also has always been our submission that there shouldn't be blanket authority given to institutions such as the children's aid societies to consent to medical treatment on behalf of crown wards or people within their care, that that has to be looked at individually. The legislation, the Child and Family Services Act, clearly provides that the only authority that the children's aid societies have is that which a parent would normally have, and the Consent to Treatment Act makes it clear that you look at the young person first. It's only if they're incapable that you go to the next level.

Overall, it's our submission that the revised legislation is a step backward for human rights and for personal autonomy. Although it states the basic principles that the Consent to Treatment Act did regarding those issues, it takes away the basic mechanisms for a review, for an appeal of decisions, and does not provide for the informing of the individual of decisions that are made about them, as well as their right to appeal those decisions. It allows for serious abuses and is definitely, in our view, in danger of a charter challenge.

Just to reiterate some of the recommendations that we made under the earlier legislation, we had recommended that the health practitioner should be required to advise all persons regardless of age, and under the previous legislation there was the cutoff of 14, of the right to appeal a finding that the person does not have the capacity to consent to treatment.

It was our recommendation, and there were guidelines established under the regulations, for the procedures for determining capacity. Again, that needs to be looked at with this legislation as well. Some of those guidelines have been incorporated, and I think that's helpful, but I think that the regulations under the Consent to Treatment Act carried more detail and were more helpful.

#### 0950

The act should provide that the minor be informed that one refusal to treat does not necessarily constitute an



absolute ban to treat, that they can actually go and seek advice from another health practitioner.

One of our earlier recommendations was that the act should apply to persons regardless of age. That is one positive thing about this legislation, the fact that an actual cutoff, arbitrary age has been removed. So we're not saying that everything is bad about this. Our organization would prefer to see amendments to the Consent to Treatment Act.

One of the other concerns that we have is that we've heard a lot of comments about the confusion out there, within the various institutions that are trying to implement the legislation, about how it should operate; doctors not knowing what test to apply and that sort of thing. I think that establishing yet another piece of legislation that they have to now read and go through is going to confuse things even more. I think that it's just going to create more problems and that we should maybe look at the Consent to Treatment Act and keeping that as the base, not throwing it out and saying, "Now we have a new piece of legislation." I think you're just going to create more confusion and the potential for more problems, like we heard with the last speakers. Those are very serious concerns that we have.

It is our submission that an advocate should be appointed for all children in care, meaning children in the care of children's aid societies who lack capacity to consent to medical care regardless of family involvement. The office of the child and family services advocate does provide that kind of advocacy to some extent. We think it should be clearly established in the legislation, whether that be an amendment to the Child and Family Services Act or incorporated into the Health Care Consent Act.

Again, as I said earlier, the composition of the Consent and Capacity Board should be specified within the legislation to include a member with expertise in the specific treatment for which the consent is being sought, as well as members with experience with the age group of the applicant; so that when you have a young person who is going before a panel, you have one member on that panel who has some expertise in dealing with youth, whether that be a paediatrician or a psychologist or someone who has dealt with capacity issues for young people.

Those are my submissions and I invite any questions.

**Mrs Boyd:** Thank you very much for coming. Where you talked about a minor child always having an override to their wishes—under 16—did you mean because the Child and Family Services Kicks in?

**Ms Milne:** No. The way the current legislation works, the Consent to Treatment Act as well as the proposed legislation, if there's an emergency situation—well, the emergency situation is the one that's most clear—and the person's found to be incapable, their wishes, if they were expressed while they were capable, govern. That's not true if the person expressed those wishes when they were under 16. Even though they were capable, if they were under 16 their wishes do not have the same force and effect that they would if they were an adult. There is the exception that the wishes have to have been expressed when they were 16 or older. You can take into consideration their wishes, but they do not govern.

**Mrs Boyd:** You would like to see it be the same for anyone who is deemed capable.

**Ms Milne:** That's right.

**Mrs Boyd:** So that's the change that you want see there. Moving on to the Child and Family Services Act, you're suggesting then that because we've already had some experience with this, the additional year's wait where the Child and Family Services Act takes precedence over the Health Care Consent Act be waived, that that just be deleted.

**Ms Milne:** That's correct. I think it's unnecessary.

**Mrs Boyd:** So there would be no period of time in which there is the override by the Child and Family Services Act.

**Ms Milne:** That's what our submission is, yes.

**Mrs Boyd:** Beyond April 3, I guess.

**Ms Milne:** The provisions are not that different in terms of the way the two acts would work together. Right now we have some uncertainty as to how the CFSA and the Consent to Treatment Act work, because it's not clear that one really takes precedence over the other. The Child and Family Services Act doesn't really speak to consent and the Consent to Treatment Act, where there is any kind of conflict, is not going to take precedence until the one year has elapsed. So we've had some difficulties and there has been at least one case that I'm aware of in which there was a problem in that area.

**Mrs Boyd:** But your suggestion is that the Child and Family Services Act permit a children's aid society to act only in the role of a parent under the Health Care Consent Act.

**Ms Milne:** That's correct.

**Mrs Boyd:** Not in a different role; in the role of the parent.

**Ms Milne:** The scenario that I can describe is one in which a children's aid society may feel it has to step in to consent to medical treatment that's being refused. If it's being refused by a young person under the age of 16 who is capable of making that decision, then the children's aid society basically has no role because it's that young person's right to refuse treatment. We don't want to see an override of that person's rights. If the young person is not capable and a parent has to step in to make that decision and the parent is refusing to consent to treatment, for example, or refusing to provide the treatment necessary, then you fit within one of the definitions of a child in need of protection. That's a different area. It should be made clear—and I think this is something that should be looked at with the Child and Family Services Act—that the right to consent should be limited to what kind of problem you're dealing with, as opposed to a blanket right given to the agency in that situation. It should be specified depending on what the specific problem is and why they've stepped in to begin with.

**Mrs Boyd:** That would require changes to the Child and Family Services Act.

**Ms Milne:** It should be done in practice anyway, but there have certainly been situations in which the courts have ordered a blanket sort of okay to consent to things without limiting it.

**Mrs Helen Johns (Huron):** Do you believe there should be an age of consent stated in the legislation?

**Ms Milne:** No.

**Mrs Johns:** Okay. You talked about part IV and children's residential settings, the rumour, if you will, or the expectation that in the regulations we could move out further than the three areas we talked about. I think, from what I was following, you would be against our moving out further with children's residential settings. Can you talk a little bit about the problems you see with that and how you see that evolving?

**Ms Milne:** Actually, I never stated that I was against that. What I'm concerned about are the same kinds of concerns that have been expressed by the Advocacy Centre for the Elderly in terms of how that works. There are some aspects of the provisions, part III and part IV, that would be very helpful in children's settings, so I'm certainly not saying they shouldn't be; I'm just asking that it be made clear. Is it going to apply or not? If it is, then we can look at how that is going to affect young people now as opposed to somewhere down the road when it's included in a regulation and there isn't the same kind of consultative process.

Certainly with respect to personal assistance plans, I think that can be very helpful the way the legislation is set up. It can be very helpful for young people so that we know what is being consented to when either a parent consents on behalf of a young person or the young person is in a position to consent themselves. We see the use of restraints on young people where the consent issue, whether or not there is consent, is pretty grey, and the people running the facilities haven't really directed their mind to those kinds of issues. It's not that we're against this act applying. In fact, we probably would be in favour of legislation like this applying to children's residential settings; we just want some certainty now.

**Mrs Johns:** From the Ministry of Health perspective right now, we're not talking about anything more than the three issues, but of course that regulation would be in the act and it would be available for, not only us, but any party that came after, to be able to expand that. I guess that's where we are right now, not with an intention to immediately come out with a regulation that expands it.

**Ms Milne:** Certainly with respect to treatment, a lot of those residential settings do provide treatment, so obviously the act would apply to those aspects. It's just the other things, the grey area, the soft area, if you will; we would like some certainty as to how that applies.

1000

**Mrs Caplan:** Many of the issues that you raised have been addressed. Justice for Children is very well-respected organization. Were you consulted by any of the ministers prior to the tabling of this legislation?

**Ms Milne:** No, we weren't. We were in the previous legislation, the Consent to Treatment Act, extensively, but not with this.

**Mrs Caplan:** I share your concern that so much is done by regulation, the impact of that. The question I have for you about that is, we're going to be proposing an amendment that would require all regulations to be gazetted, made public for four weeks before they are made law. Would you support that kind of an amendment to the legislation?

**Ms Milne:** Certainly. We would support anything that allows for some sort of consultation or at least some feedback before something becomes law.

**Mrs Caplan:** I've been thinking quite a lot about the issue you raise around single panels. The conclusion I've come to is that the chair is responsible for deciding whether it will be a single panel or multiple panel members. The chair is also responsible for the selection of who will conduct a single panel and the act fetters the qualifications that are required. It's very restrictive as to who can be a single panel representative.

Given the challenges of distance but also given the needs of some individuals to have a less intimidating environment, I can see where a single panel would be appropriate on some occasions as long as there was a way of holding the chair accountable. I've thought a lot about it. I haven't spoken to this issue until this point in time, but it was your comments, actually, about the special needs of children. I think they would be quite intimidated in a place where you had five members of a panel when they had to appear. I know that has happened. We listened to Sick Kids about them taking it to Sick Children's Hospital.

You can try and convince me but I don't think you can, because I've now come to the conclusion that a single panel may be in the interests of vulnerable people, as well as the issue that the government has been raising about the needs of distance. As long as the chair is held accountable for the selection of the single panel member, and of course you can appeal to the courts the finding of any of the panels.

**Ms Milne:** I'm sure that's much more intimidating than anything, so if a young person has to go to that step, I think we're well beyond looking at the needs of the vulnerable person.

**Mrs Caplan:** If your organization, for example, had a concern about a hearing or an appointment of a panel, you would have the opportunity to make those representations on their behalf, would you not?

**Ms Milne:** I question what you mean by having the chair accountable. Is it after the fact? I mean, the damage has already been done, to some extent. Also, I've sat in a number of tribunal situations in which there has been a three-member panel, sometimes more. In the education system, in order to obtain special education you sit before an IPRC, which often has five or six people.

**Mrs Caplan:** Not the child.

**Ms Milne:** When we represent them, the child is there.

**Mrs Caplan:** I've been there where the child is not present.

**Ms Milne:** It depends on the circumstances, but what I'm saying is that it's an intimidating process anyway. I think the safeguard of having three panel members is that you have broader expertise. It's pretty hard for the chair to appoint somebody with all the expertise I've just described in one person. You're going to have one person, who's travelling around the province maybe, making all these decisions, and I don't think that's feasible.

**Mrs Caplan:** On that one I think I'm going to have to disagree with you.



**The Chair:** Thank you, Ms Milne, for your attendance.

**Mrs Johns:** On a point of clarification, Chair: I'd like to give some of the ministry's explanations to the Clemenses on how they think they've handled them in the HCCA, so everybody can have a feel of how the ministry feels they're handled. Then you can decide if that's appropriate or if you'd like to make some statements.

**Mrs Boyd:** Could we have these tabled and then have an appropriate discussion of the tabled responses?

**Mrs Johns:** So, for example, the first one is recommendation 11. You would like me to say this section, I think, handles it, on a piece of paper. Is that what you would like me to do?

**Mrs Boyd:** Yes, sure.

#### CANADIAN BAR ASSOCIATION—ONTARIO

**The Chair:** Our next submission will be the Canadian Bar Association-Ontario, Elena Hoffstein and Adela Rodrigues.

**Ms Adela Rodrigues:** Thank you. Good morning to everyone. My name is Adela Rodrigues. I'm a co-vice-chair of the Canadian Bar Association—Ontario's health law section. On my right is Deborah Tarshis, who's also a member of that section and a lawyer at Weir and Foulds. I should add that I'm a designated capacity assessor under the Substitute Decisions Act. On the far right is Margaret Rintoul, who is a member of the trusts and estates section of the Canadian Bar Association—Ontario, and she's a lawyer with Carson, Gross and McPherson. On my left is Elena Hoffstein, who is the chair of the trusts and estates section of the CBAO and is a lawyer at Fasken, Campbell and Godfrey.

First of all, on behalf of the CBAO health law and trusts and estates sections, I would like to thank Mr Harnick for putting forward Bill 19. We're certainly supportive of the government's effort to clarify Ontario's laws and reduce bureaucracy with respect to consent to treatment and substitute decision-making, but we do have some concerns and issues we would like to address with respect to the bill as currently drafted.

We will be presenting those concerns and issues as follows: Ms Tarshis and I will deal with those that relate to the proposed Health Care Consent Act, 1995, then Ms Hoffstein and Ms Rintoul will deal with those issues and concerns relating to the proposed amendments to the Substitute Decisions Act, if that's satisfactory.

The first issue that we'll be dealing with under the Health Care Consent Act relates to the protection of the rights of vulnerable persons and is addressed at page 5 of the written submissions from the CBAO.

The health law section notes that sections 9, 38 and 55 of that proposed act provide that where a practitioner or evaluator has found a person to be incapable, nothing can be done unless the person's substitute decision-maker has given consent on the person's behalf, which is fine. However, those sections do not require that the person be advised of the finding of incapacity or of his or her right to make an application to the Consent and Capacity Board for a review of that finding.

It is the opinion of the health law section of CBAO that a system that purports to protect vulnerable persons

fails to meet its objective when it neglects to provide a means by which a person can be advised of his or her right to challenge a finding of incapacity. There must be provision for vulnerable people to be independently advised of their rights.

To just unpack that a little bit, it's important to have a system that permits treatment decisions to be made on behalf and in the best interests of those who are mentally incapable, and that's been a recognized principle in law. However, that must be balanced with the fact that persons who are found to be incapable are going to represent traditionally vulnerable groups such as the elderly or those with psychiatric or developmental instabilities.

When I say "vulnerable" I mean such things as abuse, discrimination and undue influence. The wielding of a finding of incapacity can perpetuate that vulnerability and certainly that is acknowledged by this bill to the extent that it continues to provide a mechanism by which a person can appeal a finding of incapacity. But such an attempt at balance is useless if the person found incapable is denied the protection of being advised of that label that's being placed upon them or is further denied the opportunity to be in an unbiased way advised of their right to challenge such a finding.

These same considerations apply, I submit, with respect to findings of incapacity under the Substitute Decisions Act, and that is directly addressed by the trusts and estates section in the first paragraph of their submission at page 8.

Ms Tarshis will deal with the rest of the health-care-related submissions.

**Ms Deborah Tarshis:** The next issue that we address is the definition of "treatment." The definition of "treatment" excludes "personal assistance service." A personal assistance service could include certain controlled acts, for example, inserting a urinary catheter. It is not clear presently where the government intends to require informed consent where a controlled act forms part of a personal assistance service.

Our next issue deals with informed consent. The person responsible for obtaining informed consent is the health practitioner who proposes the treatment. There are, however, practical difficulties as to when and by whom informed consent is to be obtained. For example, when the person who orders the treatment is not in contact with the person who is to receive the treatment, who is responsible for obtaining consent? Or when the physician orders an X-ray but the medical radiation technologist who is to apply the X-ray may be more familiar than the referring physician with the risks of radiation, can the technologist assume that informed consent has been obtained?

The health law section recommends that a health practitioner who proposes treatment be defined by Bill 19 and that more thorough guidance be incorporated with respect to the role of health practitioners who do not propose treatments but who administer treatments.

#### 1010

The next issue deals with opinions of health practitioners. Section 23 deals with the administration of treatment in an emergency without consent. The health practitioner is required to form certain opinions before

treatment can be administered. With respect to subsections 23(2) and 23(3), the practitioner is required to note in the person's record the opinions held by the health practitioner. With respect to subsection 23(4), which deals with an examination or diagnostic procedure which can be performed without consent in order to determine whether there is an emergency, the health practitioner also has to form certain opinions but it is not required that the health practitioner note such opinions in the person's record.

It is the view of the health law section that the requirement to note the opinions in the person's record should also be applicable to an examination or diagnostic procedure.

Our next issue deals with admission to a care facility. Section 44 of the bill sets out situations in which an admission to a health care facility cannot be authorized, that is, where the incapable person intends to apply to the Consent and Capacity Board to challenge the finding of incapacity or where the incapable person intends to apply to the Consent and Capacity Board for the appointment of a representative. An exception to this requirement is for a stay of a definite number of days. However, "a definite number of days" is not defined and could constitute an exorbitant length of time for a person who is being admitted to a care facility where he or she does not want to be.

Lastly, we'd like to address the definition of "restrain." Section 6 of the bill preserves the common-law duty of a caregiver to restrain or confine a person when immediate action is necessary in order to prevent serious bodily harm to the person or others, but there is no definition of "restrain."

It is the view of the health law section that "restrain" should be defined in the same manner as "restrain" is defined in the Mental Health Act.

**Ms Elena Hoffstein:** I will start by saying that the trusts and estates section supports the amendments that have already been introduced which will reduce the level of bureaucracy associated with substitute decision-making while retaining protections for vulnerable people in order to deal with those cases of abuse in the population. We support the legislation which sets up systems which work for the general population while allowing for protection where abuses exist, rather than legislation that is directed at the worst-case scenarios and forces all cases into the same mould.

My comments this morning will address some of the submissions that have been made, and I'll just highlight some of them. The first is on page 8 of the submissions and deals with the repeal of the Advocacy Act. We welcome the repeal of the Advocacy Act as a move towards simplification of the system of establishing a substitute decision-maker. However, in the absence of advocates, we believe that vulnerable people still need a mechanism whereby they can discover their rights in the overall process.

We therefore would like to suggest that the certificate of incapacity that must be provided to the person found to be incapable should have as part of the required format a clear statement of the rights of appeal that are available to the individual and how such an appeal can be insti-

gated. Individuals found to be incapable under the Health Care Consent Act should also be provided with some form of advice as to the finding of incapacity and the rights of the person who's found to be incapable.

The second comment which we would like to underline is also found on page 8 and it deals with the amendments simplifying the witnessing requirements and elimination of validation for personal care powers of attorney. We support the repeal of the witness attestation requirements which are set out in subsections 10(3) and 48(3) of the Substitute Decisions Act. We have found that these witness attestation requirements are too onerous. In addition, we are concerned that witnesses might be drawn into litigation in the future as potential defendants if they witness the execution of a power of attorney in circumstances where it was subsequently established they should have had reason to suspect that the grantor was incapable at the time the document was executed. In light of these requirements, we have found that many financial institutions and health care providers have adopted policies which preclude their employees from acting as witnesses. These policies have made the execution of these documents difficult and costly.

We therefore commend the proposed changes reducing the potential liability of such witnesses and reducing the costs and difficulties of execution. The change means that the witness attestation requirements applicable to powers of attorney are consistent with those applicable to other documents, such as wills.

We also agree with the elimination of the restriction preventing a child of the grantor from acting as a witness to the power of attorney. We feel that adds nothing to the safeguards the legislation has put in place for the benefit of grantors.

A third point I'd like to make is that we commend the elimination of the complicated validation process for powers of attorney for personal care. We have found this process to be cumbersome, time-consuming and costly, and question the related benefits.

I'd like to move to a definition of "treatment" and the regulations regarding release of information. We support the revision to the definition of "treatment" found in the Health Care Consent Act. The revised definition clarifies that treatment does not include the assessment of a person's capacity with respect to treatment or an assessment under the Substitute Decisions Act of a person's capacity to manage property or of a person's capacity for personal care for the purposes of the SDA or the assessment of a person's capacity for any other purpose.

We believe this proposed amendment eliminates the necessity of a court application in circumstances where a person cannot give consent to an assessment. We would like to suggest, however, that further amendment be made to assist health care providers in dealing with the confidentiality concerns in other legislation that applies to them, and we believe that regulations should be considered to ensure that professional obligations of assessors as assessors and their obligations to their individual professional bodies are not in conflict.

I'm going to move to opting out of statutory requirements, found on page 13 of the submission. The Substitute Decisions Act imposes a number of duties on



attorneys and establishes a standard of care which must be met when carrying out those duties. We have found that clients are surprised when they are advised of these provisions and the onerous burden that the client is potentially imposing on a family member or friend who is asked to act as an attorney. In addition, many of the soft duties which are imposed upon attorneys are based on assumptions concerning family units that may not be relevant or applicable in cases of many clients. As a result, many clients would like to have the opportunity to eliminate or modify some of the duties which are imposed. At the present time there is nothing in the statute that permits opting out of these provisions of the SDA.

We would therefore recommend that the Substitute Decisions Act be amended to expressly permit a grantor of a power of attorney to opt out of these provisions if he or she considers it appropriate in the circumstances. We point out that an individual is entitled in most circumstances to specify the standard of care and obligations imposed on executors of their wills or trustees of inter vivos trusts that they establish. We feel that a grantor of a power of attorney should be similarly entitled to do the same thing in the context of a power of attorney that he or she is granting, and we see no justification for the current inconsistency in the law.

The last point I would like to make is on page 14, and it relates to revocations of powers of attorney, a technical point. The current legislation provides that a continuing power of attorney is revoked when a subsequent power of attorney is executed. Many clients execute limited forms of powers of attorney with their banking institutions and other financial institutions without realizing the potential adverse impact on a general power of attorney which they may have earlier executed. And this is, as I said, done inadvertently often and without recognition by either the institution or the donor of the power of the effect of signing the limited power of attorney.

1020

We would like to recommend, therefore, that there be further amendment to provide that it's only when a new general power of attorney is executed that it revokes a prior general power of attorney.

I conclude by stating that we support the government's commitment to protect the interest, dignity and autonomy of vulnerable people. We support the proposed amendments which have been referred to in our comments and further in our submissions, and we are grateful for having been given the opportunity to identify practical and cost-efficient solutions to the problems we've encountered in our practice. Thank you very much.

**Mrs Johns:** I just have a couple of questions about the health section of it. In the admission to a care facility on page 7, you suggest that we should have a definite number of days that we allow someone to stay in a centre as a result of crisis. How many days would you people recommend?

**Ms Tarshis:** We don't have a specific recommendation. We think thought needs to be given to put some definition to that, otherwise any number of days is a definite number. It could be 482 days. That is a definite number of days.

**Mrs Johns:** So you just want to see a definite number of days in this section?

**Ms Tarshis:** We want consideration to be given to that issue.

**Ms Rodrigues:** I don't think we understand quite what the point that was trying to be addressed was by the exception. If you could provide us some insight into that.

**Mrs Johns:** The thing that comes through in your presentation, I think probably the loudest in the health section, is the issue of the health practitioner telling people about incapacity and giving them rights advice or telling them where they can go from there. I'm somewhat surprised by that as a result of the fact that health practitioners in a number of cases believe it should be regulated through the colleges, through guidelines by the colleges, and in fact you have the same kind of system where you have a college that regulates you also, and so I was surprised that you may be implying here that colleges who set up guidelines wouldn't be substantive enough. Are you suggesting that by what you're saying in this area?

**Ms Rodrigues:** We were talking about the number of days and—

**Mr John L. Parker (York East):** Let me help you, because we're talking about two things here. Your question was about the number of days. I think the answer to that is to distinguish between a temporary stay and an indefinite stay, where you put somebody in for a defined period of time versus putting somebody in indefinitely. So think of that when you read that section. But the question that was just asked was on another subject—

**Ms Rodrigues:** No, I know that, I just wanted to make sure we understood that because of what of Ms Tarshis said. We were concerned because the principle of days is significant in providing a right to somebody. The three days may not seem like much to you, but it can seem like a lot if someone desperately does not want to go a particular facility. That's why we just wanted to clarify that for any future reference.

But what we were talking about with the college, did you want to address that in terms of—

**Ms Tarshis:** What I don't understand in the question is, are you dealing with the comment that deals with setting up a system where vulnerable people are made aware of their rights under the act? I'm not sure there's any obligation under the act imposed on health practitioners to make a vulnerable person aware of the finding of incapacity or aware of their rights to appeal that finding. We're not expressing a view as to what the best system would be to do that under the act, but we do feel that it should be addressed.

**Mrs Johns:** So you believe it should be actually in the bill, it should be part of the legislation, that there is some need to do that? You don't think it can be done, for example, through the health practitioner's act where the minister says to different colleges that they have to prepare guidelines that their members are accountable to?

**Ms Tarshis:** If what you're saying is that the government intends by regulation to impose that obligation on health practitioners, that would be one system of dealing with that.

**Mrs Johns:** It isn't regulation.

**Ms Tarshis:** I'm not aware of any current obligation, either in this statute or in the Regulated Health Professions Act or in the specific acts governing the specific health professions that would impose an obligation on a health practitioner, absent either statutory or regulatory requirements to do so, to advise patients of the rights under this statute.

**Mr David Ramsay (Timiskaming):** Thank you very much for your presentation. It's very thorough and for me it has brought up some points that haven't been brought up before. I think the government should be listening to these and I hope they are.

I have one question on the rights advice, because I agree with you for sure that obviously somebody who has been found to be incapable should be informed, and also they should be informed of their rights to appeal. But you also say here, and I'm not sure how we're going to do that yet—and I think the government may move on this; I certainly hope so—there must be a provision made for vulnerable people to be independently advised of their rights. With the Advocacy Act being repealed, who would you propose maybe do that? What mechanism should be employed?

**Ms Rodrigues:** Because we haven't heard all the interest groups' submissions, and because that has so much to do with policy and economics and that sort of thing, we didn't come up with a specific plan. We'd be happy to be involved in assessing the different options that come up.

I think it's a consideration that must be addressed when looking at the different systems. For instance, if you're saying the health practitioners are going to be doing it, are we looking at issues of bias? Are we looking at the issues that directly affect a vulnerable person under those circumstances? We have to realize that what we're trying to do here is create a balance. There's no point in creating this whole system of obligations and duties and everything if we don't have a balance, a balance of protecting that person who truly is incapable and sitting there with their money in a bank and starving and not getting proper decisions made or whatever—balancing that with protecting them from being abused.

You also want to look at the doctor-patient relationships that exist and all that sort of stuff and how that works, but you do have to look at those issues. That's what our concern is today, to make sure those principles that have been espoused through the courts and through our laws are represented in whatever is finally determined as a viable rights advice service.

**Mr Ramsay:** Without making it too complicated, what I'm thinking about is that if the health care practitioner would be mandated through statute to bring forward that information and then it be duly noted on the chart possibly so that we have some documentation. But we don't have forms, get it as complicated as it is today, but at least make sure that it is given and noted. Maybe you might want to think about that.

**Ms Rodrigues:** I think anything is a start. Obviously, that's better than nothing, certainly. I'm not saying that's totally inappropriate or anything, but you do want to make sure: Is that practical? Is that something a physician

is going to be able to do? When you're dealing with a health practitioner, you're dealing in a best-interests model. They're under certain stresses and obligations, and there's family. Are they going to feel that they can give rights advice in an objective manner? Can they divorce themselves from the relationship they have on a clinical level, "I told you this now. I think you're incapable. Here are your rights," and be able to stand back and just note it and see what happens and that sort of thing?

1030

I'm not equipped to answer that, but raising that question and looking at it, that's satisfactory because you're questioning exactly what we're questioning: Is that going to be enough? That takes a lot more in-depth looking. Also, there are the practical realities of what people have to face in those situations.

**Mr Rosario Marchese (Fort York):** Thank you for your submission. There are a few things that are useful in terms of your considerations around admission to a care facility and definition of restraint. I agree with that.

I have some serious concerns about your repeal of the Advocacy Act, on the other hand. It seems odd that such a body would say, "We support the repeal of advocacy." On the other hand, you say, "We're concerned that all vulnerable people be given access to some of the sources of advice and assistance." I'm not sure they contradict each other. What you suggest and what the Advocacy Act proposed is, in my view, very complementary.

The Advocacy Act was designed to assist elderly and disabled people who cannot speak on their own behalf to have a voice. That was the intent of it, and it remains my conviction that's something we need to do as a government. Your suggestions are complementary, not in contradiction.

**Ms Margaret Rintoul:** I think perhaps what has to be said is that, in a perfect world, an Advocacy Act provision might well be an ideal. In an imperfect world, with a lot of budget constraints and everything else, my colleagues and I were very concerned that the whole concept under the Advocacy Act just built up an enormous bureaucratic system that carried with it a great deal of expense, and to some extent the initial goal of making sure that vulnerable people had somebody to tell them that they had some rights got a bit lost in the whole bureaucratic system.

To that extent, in the case of legitimate private guardianship scenarios and statutory guardianship scenarios and treatment situations, the Advocacy Act very much got in the way of a lot of things that were needed at the time and still are needed. So for that reason, we thought it was appropriate to go on record that we did support the repeal of the Advocacy Act itself and the system and mechanism that it was creating.

I accept your comment that it is a little contradictory to say, "Well, somebody's got to give some advice." I don't think it's contradictory at all, because I don't think it's contradictory to say that you don't need an enormous bureaucratic body but, at the same time, you have vulnerable people who do have rights and who need those rights protected in some way. But do you need to protect them by creating this huge umbrella organization and body to do so? There's got to be a way that is a cost-



effective delivery of those rights, that doesn't create its own empire.

**Mr Marchese:** Mr Chair, quickly, I want to state my profound disagreement with the rationale that she provides and that the others might be agreeing to.

**Mrs Boyd:** We disagree because of conflict of interest, basically. There's an inherent conflict of interest if the person proposing the treatment is the person who makes the decision of incapacity and the person who's responsible for giving rights advice.

**The Chair:** Thank you. Your half-hour has elapsed. We appreciate your coming today to share your wisdom.

#### CONCERNED FRIENDS OF ONTARIO CITIZENS IN CARE FACILITIES

**The Chair:** Our next submission is the Concerned Friends of Ontario Citizens in Care Facilities, Freda Hannah. Welcome, Ms Hannah.

**Ms Freda Hannah:** I was to be accompanied by my other advocate today, Eleanor Murphy, but Eleanor is ill and was unable to come, so I have Heather Graham, who is also a board member and helped write this brief.

I want to say good morning to all members of the committee and I want to thank you for giving us the opportunity to present this brief. We will be addressing only advocacy. We'll leave the other two bills up to the legal profession.

Just as an aside, I would like to say that the reason I have stayed with this organization for such a long time has been my desire to improve conditions in long-term-care facilities as a senior. After all, what I see when I look at long-term care is really a window on my future and your future.

Cognitively impaired seniors are the most disadvantaged group. It has been estimated that between 50% to 80% of residents in long-term-care facilities have mild to severe cognitive impairment. With about 56,000 residents in nursing homes and homes for the aged, we can readily see the number of residents who might need an advocate. This does not account for 12,000 presently residing in chronic-care hospitals, as well as the thousands who are living in rest and retirement homes. We must also include those being cared for in the community by their families and support services. Of course, population aging is on everyone's mind and demographics are constantly reminding us that there will be more old people, particularly those over 85. We are now looking at people who are in their 90s and 100 years old.

Concerned Friends is a volunteer consumer organization dedicated to improving health care in long-term-care facilities.

Our goals are to address the issues of quality care, both physical and emotional, and the general conditions facing residents in nursing homes, charitable homes and homes for the aged. This we describe as individual advocacy. We also want to bring concerns about conditions and quality of care to the attention of the provincial government and to work for constructive changes in statutes and regulations. This we call systemic advocacy. We meet with the residential services branch approximately once a month to discuss our concerns.

We also want to provide information to residents and their relatives concerning their rights and responsibilities under government legislation, and to teach family members how to advocate on behalf of their relatives, if this is possible.

The work of Concerned Friends is performed by volunteers, with the support of membership fees and donations. In order to retain an independent perspective on long-term-care issues, the organization functions without external funding.

Concerned Friends believes that there must be a responsive, effective and accessible advocacy system for residents in long-term-care facilities and their families. Residents and their families must have access to advocates who are trained to operate in the long-term-care system, funded by the provincial government and independent of any actual or perceived conflict of interest. Vulnerable elderly persons cannot rely on family members, facility staff or volunteers to advocate for them in all situations.

The general public is largely uninformed about long-term-care services in the community and the rights and responsibilities of individuals within the service delivery system. The public lacks information about ways to resolve problems within the system. We have had 15 years of experience in knowing that.

Many residents have no family. I think the nursing home association gave you these statistics as well. It's at the back of the report, Appendix F: In 8.89% of cases, or 4,894 residents, the family never provides assistance or the resident has no family. In 28.96%, the family is in contact with the resident at least once a year. You can see there are a lot of people without friends, relatives.

#### 1040

Often, family members are so emotionally involved that they may experience difficulty in putting the needs and the wants of the vulnerable person in perspective. For example, some family members are handicapped and they in turn are trying to advocate on behalf of the resident. Family members may not be able to provide effective advocacy—and this is what I was saying—because they themselves are vulnerable. Family members may not know how to advocate or may be afraid to act for fear of reprisals against the resident. When I first started volunteering with this organization, I found that one of the most amazing parts, that people are afraid of reprisals. But I found it to be true.

Facility staff are dependent on the organization for employment and thus are unable to fill the role of impartial advocates. In fact, staff have called us asking us to be advocates for people, or even their advocates.

Volunteer advocates are too few in number to meet the demand. Without any legal status, volunteer advocates are limited in what they can achieve.

Concerned Friends has operated since 1980. The organization therefore has more than 15 years of experience with volunteer advocacy. Concerned Friends supported the concept of a formal system of paid advocates because it knows, through years of personal experience, that volunteer advocates are too few in number to meet the needs of residents of long-term-care facilities.

Currently we receive over 400 telephone calls each year, of which approximately one quarter, 100 calls, relate to concerns about quality of care, conditions in facilities or residents' rights. At present, Concerned Friends has only two members who are sufficiently trained to act as advocates and who are able to give advocacy activities the time they require. Two advocates are not enough to meet the demand. People from all across Ontario contact Concerned Friends. Many callers can only be given telephone advice because the time required to become personally involved in individual cases is enormous.

Despite frequent recruitment attempts, Concerned Friends has never had more than four advocates over the past three years. Therefore, we can't publicize what we do or look for people who may need our help because we could not meet the increase in the demand.

Concerned Friends lacks the resources that are required to recruit, train and supervise advocates to work in the long-term-care system. Recruitment would be challenging, whatever the resources, because of the time commitment required of volunteer advocates. Training needs are extensive. They include the full knowledge of the long-term-care system, the provincial standards for long-term-care facilities and appropriate community resources, which tells you that you have to be more than a friendly volunteer to do this kind of work if you're going to help the person.

Finally, in order to ensure quality service, a large group of volunteer advocates would require supervision and evaluation mechanisms which volunteer organizations cannot possibly implement.

In the following cases, we share some of the hopelessness felt by those unfortunate people who have been caught in a system which is unable to effectively ensure their wellbeing. The only help available for too many years for these individuals has been the efforts of volunteer advocates who attempt to respond, with resources inadequate to the demand.

The following story depicts some of the problems faced by many residents in long-term-care facilities and their families.

Diagnosed with a heart condition, congestive lung disease and little short-term memory, Jane was inappropriately placed on a heavy care floor where all other residents were suffering from severe forms of dementia. Already opposed to the idea of placement in a facility for the aged, it was impossible for her to adapt positively. An attempt was made to have her moved to another facility. She was later moved but to another inappropriate setting so that Jane returned again to the original facility.

By this time, Jane's condition had deteriorated and she required considerably more care. A three-week stay in hospital for breathing related problems left her unable to walk. She was quite confused and much more dependent. A relative who visited Jane told Concerned Friends that she was greatly concerned that Jane was not getting the assistance she required. She was often in distress.

On one occasion when the relative visited, Jane was in conflict with an aide who denied her bed was wet when Jane said it was. Two pads were wet; the aide stated only one pad was wet. Eventually, the aide acknowledged that

two pads and sheets were wet, and we find this over and over, arguments going on that eventually lead to a lot of problems. The aide took her to the bathroom while the relative looked for a clean nightgown. There were no clean clothes despite the fact Jane had numerous nightgowns and the family paid for personal valet service. Despite this, several items of clothing disappeared.

On another occasion, Jane was found crying because she was cold. She was lying in bed wearing a thin blouse, sleeveless jacket and covered with a sheet. No one could explain why she was not dressed as there were clothes lying around.

Jane had fallen numerous times and was covered with open wounds and bruises. On one visit a relative found her lying on the floor in an open doorway. Despite many previous falls she did not appear to be restrained in her wheelchair. On this occasion and at other times she was not wearing underpants or hose.

Another resident in Jane's room is routinely left on the toilet for up to half an hour while the harried aide attends residents in other rooms. Residents are wheeled into the dining area and parked at a table over an hour before a meal is served. Staff talk to each other rather than residents at this time and there appears to be little effort made to talk to residents and orient them to where they are going. When a friend brought a light supper in to celebrate Jane's birthday, an attendant took Jane to the toilet. When the friend went to see why she had not returned, she found her undressed and in bed. This was at 6:15. Residents are in bed by 7, presumably for the benefit of staff, and we're the first to admit we feel there is a shortage of staff in homes for the type of people we're looking at today.

Jane's family described to Concerned Friends what they see when they are visiting and what they fear happens when they are not there. One attendant in Jane's facility stated that she had 13 people in her care. All the residents appeared to be disoriented and/or physically disabled and needed as much attention as an infant, yet it would be illegal to have the same ratio of staff to children in a day care setting.

Jane's family was told that Jane would adjust quickly to life in a long-term-care facility, and that due to her loss of memory she would find comfort and security in the routines. This was not the case and Jane was constantly asking what she did wrong to deserve such treatment. There were few staff available to provide mental stimulation, kind words or even rudimentary care.

It is difficult and heartbreaking for families to leave a relative in long-term-care settings. Jane's family told Concerned Friends that they and Jane all hope she will not have to live much longer if this is all there is.

I must say that in some cases families are professional people and they are overawed with what they deal with in some homes. We're not talking about all homes; we're talking about some homes.

They were unable to resolve their problems through meetings with the staff at the long-term-care facility or through bringing in the compliance adviser. When you notify the compliance adviser of a problem in a home, it takes two weeks for the adviser to get out to the home because they too are short of staff. They turn to us for



help and we continue to work with the group. If the person, Jane, is physically able to move to another home, a better home, then we would help try to support that.

**1050**

I'm running a little short on time. In the case of Joe, I'll leave you to read that. We could write a book on this one. It took almost a year to get things sorted out.

I would like to discuss what is in the box, Sally was an example of an individual who is not capable of advocating, independently, on behalf of a relative. She came to me with her problems. I worked with her. Fortunately she kept a diary, so she had every incident documented, which was more than the staff had done.

We dealt directly with the residential services branch. We provided advice in dealing with the residential services branch. We indicated how to report incidents, maintain effective records of the events, and that means any staff names, times, dates and incidents that happened. We found another home for Joe. We met with facility staff, Sally and the local MPP trying to resolve these problems.

What happened is that some of the staff either left or were let go. When we initiated all these concerns or investigations, we found there were a lot of systemic problems in that home; there were many of them. So a lot of families were having problems. This is what we find usually; it's not just one family that calls us; there are a lot of families.

We do not promote firing staff. We prefer to see staff retrained or receive more training. We'd like the owners to take more responsibility in the staff they hire and then look at the kind of care that's being given in the home rather than have staff leave. We don't promote that.

We believe that there must be a responsive, effective and accessible advocacy system for residents of long-term-care facilities and their families. Residents and their families must have access to advocates who are—we've mentioned all this before. Again, vulnerable elderly persons cannot rely on family members to—we, as a group, would be happy to assist in the development of an effective advocacy system which would address the deficiencies of Bill 19. Please note that Concerned Friends has prepared a number of documents which suggest principles and features of effective advocacy systems and are available upon request.

We've included bios on our board of directors. This is the president's activities related to systemic advocacy; that's mainly what I do and what the board does. This is a great deal of work, because I'm retired and Heather works. There are only two board members who don't work, so we get to do all the going to meetings; they're always during the day. We're very busy in that way. We deal with all these people. Mainly it's for educational purposes and to make people aware of what's happening in the homes.

In the case of George Brown College, we help the staff prepare the curriculum, because we know what's going on. I review all of the compliance review reports where there are a lot of violations.

We have a copy of our annual report, and our publications mention that. We also have a list. We keep tabs on all those homes that are under enforcement. During 1995,

there were nine homes under enforcement at various times. The total number of residents in these homes is 1,535. You may look at nine homes, not very many out of over 400, but when you look at the number of people who are affected by this, it looks quite different. Two of the nine homes have been under enforcement for one and a half years. In both homes, the enforcement officers are still reporting that residents are at risk under the personal care category. The total number of residents in these homes is 446.

**The Vice-Chair (Mr Ron Johnson):** Thank you, Ms Hannah. We've got time for some questions now.

**Mrs Caplan:** Nice to see you again. My question is, were you or Concerned Friends consulted by the ministers prior to the tabling of this legislation?

**Ms Hannah:** You mean the latest? No.

**Mrs Caplan:** I'm trying to find out who they talked to prior to the tabling of the legislation. They refuse to tell us who. Anybody I ask says no, so I'm becoming quite sceptical about if there was really any consultation; I suspect there was not. There is a consultation, sort of, taking place now under Marilyn Mushinski at Citizenship. I'm assuming you're part of that.

**Ms Hannah:** Yes, we were there.

**Mrs Caplan:** Were you told that there would be no new legislation as a result of that, sort of, in advance? I understand that was one of the principles.

**Ms Hannah:** Yes. There won't be anything that involves funding. We're willing to work. We didn't agree with everything in the Advocacy Act either. We had a lot of problems with some things. We feel that there is room for volunteer advocates, but we should be able to work with paid advocates.

**Mrs Caplan:** Coordination.

**Ms Hannah:** Yes. But you have to be trained. You can't be a friendly visitor and actually be an advocate.

**Mrs Caplan:** Actually, I share those concerns, and I also think that a shared advocacy model, where government's role was more in seeing that there was coordination and training, and identification of existing organizations and perhaps looking to fill in the gaps, is a much better approach than the cumbersome and expensive previous model. But I despair that the preconditions of the discussions that are going on would preclude that from happening. From what you're telling me, they're not likely going to see anything that would see government in a coordination role.

**Ms Hannah:** That was my understanding. Of course, we were very upset and very disappointed because my predecessor worked for 15 years for advocacy. We've been out in front of Queen's Park marching many times when we thought it wasn't going to happen. We had a lot of support from many people.

**Mrs Boyd:** Thank you very much for coming. I know you've been working on this for many years. I certainly have been aware of the reports you've put in, and I know how dedicated the organization has been to a form of advocacy that deals not only with the individual, which is what you are able to deal with, but that takes some government responsibility, as well as community responsibility, for the kind of systemic advocacy you do.



You've given us some very good examples. Unfortunately, in these examples, family were caring and loving, and in spite of that people found themselves in situations where the family didn't have the clout that they were able to deal with this. That's the real issue: unless there's someone who has legal access both to the client and to the records and the information, it's very hard to advocate on behalf of these folks, isn't it?

**Ms Hannah:** For example, in a second case where we would like to have been able to go to the doctors in the hospital and say, "What are you going to do now, because you've said this is wrong," we can't get information from them. What we find are doctors who will send residents right back into a home they've come from with problems and we can't do anything about that.

1100

**Mr Frank Klees (York-Mackenzie):** Thank you very much for your presentation and also for some of the specific examples that you've given to us. It's certainly very helpful. Maybe one of the things that we as members can do is, rather than sitting here, get out and visit some of these homes ourselves and maybe have some direct impact that way.

I want to thank you on behalf of the government for your willingness to participate in the stakeholders' meetings with us. I'd like to clarify perhaps a misunderstanding that took place at that meeting when you drew the conclusion that there would be no funding at all for advocacy. That is not the case. Certainly, it won't be \$18 million under the previous circumstance, but we have stated very clearly that we believe in advocacy. What we want to do is work with groups such as yourselves and come up with something that's practical and affordable that addresses in a very real way the issues that you bring to our attention.

What I hear from you is that the need for coordination and education is critical. We look forward to getting some further input from you as to exactly what the role of government is going to be. I see you've got 600 members and you mention that only about two of them are adequately trained. I'm assuming that of those 600 members, some would be willing to participate and expand their knowledge to help us in this process.

**Ms Hannah:** We really work with the board. A lot of our members are seniors, and we've found over the last few years some of them can't even come out to our general meetings any more. So we do have our newsletter that we send out to everyone and try to keep people up to date. It's our board.

There are other groups throughout the province who have called me. The latest one was someone in Thunder Bay. They would like to have an organization like Concerned Friends, but they can't afford to come here and we can't afford to go there to help them out. It takes a tremendous amount of work just to get an organization started, because it is a really long commitment.

**Mr Klees:** So that area of coordination is something that perhaps you feel we could work together on.

**Ms Hannah:** Yes. I know there are other groups. There was a group in Windsor and a group in Ottawa at one time, but they just couldn't keep them going.

**The Vice-Chair:** Thank you for your presentation.

## SURVIVORS OF MEDICAL ABUSE

**The Vice-Chair:** The next presentation will be Sharon Danley, Survivors of Medical Abuse. Welcome.

**Ms Sharon Danley:** I'm afraid I can't be quite as eloquent or pleasant in my preparation for today. I tried to take the rage and the anger that I see on a daily basis and bring it back to where it belongs. We're here once again before a Legislature that is a fascist-inspired body of lawmakers, hell-bent on assaulting the vulnerable: the poor, the elderly, disabled, women, children, victims, me, the women I represent and the children I love; once again another ominous bill, this time it's number 19.

For the record, I represent a group of women who have come from surgical violations and sexual assaults inflicted by the medical community, as well as character destruction, unconscionable diagnosing, drugging and human experimentation by their dangerous psychiatric brothers. Then they suffer further victimization brought about by out-of-touch judges, misogynistic defence lawyers and a court system that fails at every turn.

Next, they suffer the cascading effects of being brought into a social service system that humiliates, shames and degrades them further, and finally but certainly not least, a government that keeps ignoring their pleas for protection and rights to amend. But will you listen to our expertise and solutions? I think not. You see these women and children as nothing more than welfare leeches or psychiatric bums that bleed the good Ontario taxpayers' pocketbooks.

You would far sooner listen to your corporate, power-hungry capitalists and the economic agenda you both continue to market as your excuse to continue bulldozing any moral attempts at keeping our Charter of Rights and Freedoms intact. Yes, the Charter of Rights and Freedoms, that almost forgotten law which this country is supposed to be built on and stand for. Let's take a closer look at part of the charter just as a little refresher.

"15(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination....based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

Bill 19 makes incredible changes to three pieces of legislation. It repeals the Advocacy Act, eliminates the Advocacy Commission, makes amendments to the Substitute Decisions Act and replaces the Consent to Treatment Act with the Health Care Consent Act. Can this government do anything in moderation?

For almost two decades, advocacy groups and consumers have recognized that many disabled adults and seniors are not being treated equally, and are more vulnerable to horrendous neglect and abuse because many are institutionalized. The Advocacy Act was born in 1992, out of this long-overdue need. You know that several reports have been commissioned and extensive studies done and they all state the same thing. The need is there and it is paramount: the promotion of respect for the rights, autonomy and dignity of all persons; the assurance of due process where one has the freedom to control one's own life and body; and the protection of the most vulnerable from abuse, neglect and exploitation. These are the cornerstones of the act and the charter.



Why do we keep coming here, wasting precious time and money, talking about what's already been discussed and pleaded for? It's quite apparent, as was shown during the Bill 26 public proceedings, that you all need to pay a visit to an ears, nose and throat specialist. The cries of the people aren't getting through to your grey matter. If you were listening at all, you wouldn't propose, let alone pass, this kind of draconian, irresponsible legislation.

There is nothing equal, fair or right about repealing the Advocacy Act.

"12. Everyone has the right not to be subjected to any cruel and unusual treatment or punishment."

The Substitute Decisions Act breaches the confidentiality of medical records in much the same way that Bill 26 does. Anyone just stating the intention of applying for guardianship can see a person's clinical file. Service providers can become the guardians of an incapable person's property. It is an open door for abuse. The incapable's finances could be stripped. Adult children can act as witnesses during the execution of power of attorney even when there is a conflict in the family as to the heirs of the estate. As well, nobody has to be screened before becoming a guardian.

But the most callous, sickening, disgusting part of this act is that it will no longer prohibit a substitute decision-maker from consenting, on the incapable's behalf, to the use of electroshock, or cattle prods, as aversive treatment.

Why in God's name does this government refuse to look at the cruel and unusual treatment in this appalling act?

"7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."

The proposed Health Care Consent Act removes all references to rights advisers and eliminates the requirement that rights advice be provided to a person found to be incapable. This means that there is no obligation on a health professional to tell patients that they have been found incapable, what their rights are and that they can appeal this decision.

1110

The act permits emergency treatment without consent of a capable person if the communication required in order for the person to give or refuse consent cannot take place because of a language barrier or because the person has a disability that prevents the communication from taking place.

The act provides health practitioners with protection from liability in respect of decisions concerning treatment or admission of an incapable person to a facility for treatment.

The board is no longer required to sit in panels of three to five. One board member can sit alone, and they don't even have the expertise and evaluating capacity.

I can't for the life of me see "the right to life, liberty and security" in this one.

Once again without one penny of funding, our group cannot hire the legal minds to help us find our way through this massive, destructive bill in order to totally understand all of the nuances one must, so unfortunately, we cannot fully understand all the legal intricacies that

we need to that this point. Therefore, we will not attempt to waste one minute in dragging out our pleas and compete for justification of our ideas on solutions.

You've heard it all before and no doubt you will hear it here again during these public hearings. Our solution, simple and to the point: Keep the Advocacy Act of 1992. Not only does it give minimal protection to our vulnerable, it creates jobs. Wow, what a concept.

As our neighbours just to the south of us experience, there is in every state, in all of them, a protection and advocacy office funded by the US government. As I said earlier, the Advocacy Act was created out of a great need, and a lot of time and money have been spent bringing it to fruition. Now you Tories want to just throw it out. How unconscionable of you; how immoral of you. How sad for us, our loved ones and especially the ones who have no one.

There will always be those politicians and lawyers who will twist and distort reasonable laws to suit their own agendas, but the proposals of this Tory government to make law out of Bill 19 outright sanction and foster these kinds of activities with a licence and a blessing.

I'll leave you with this thought to ponder: Remember, all of you are only one car accident away from being in a vulnerable, disabled position. You too could develop a neurological dysfunction or be violated into a traumatized state of mind. You too will be old one day and may lose most of your body functioning; you too will reap the legislation you sow if you pass this bill.

Thank you. That's all I have to say. If there are any questions, I'll be happy to answer them.

**Mr Marchese:** Thank you, Ms Danley, for the presentation. I understand the anger that you feel. I hope, for the members of government, that they can separate the anger to look at a number of points you've made that many others have made as well. Many have commented—for example, on page 4—that one board member is simply inadequate. To leave the decision of one's life with respect to capacity or incapacity in the hands of one person is a problem. We disagree with that too. We believe in all cases you should have a panel of three people at least. We would be happy with three.

In terms of protections from liability with respect to decisions concerning treatment and so on, other people have raised this issue as well, so you're not the only one. Other areas that you have raised are many, and others have agreed with you with respect to confidentiality of medical records. "Service providers can become the guardians of an incapable person's property," and that's a conflict—many others have said the same thing. "Adult children can act as witnesses during the execution of power of attorney"—many have agreed this is a conflict and a problem and we should be dealing with that.

With respect to advocacy, countless people so far have agreed. There have been a number of them who haven't agreed; one of them today was the Canadian Bar Association—Ontario. And some medical practitioners have come forward disagreeing with that. We, on the other hand, agree that we need advocacy and the government needs to be involved. They disagree; they said government shouldn't be doing advocacy. We think that if

government doesn't do it, they're abrogating themselves from an important responsibility.

**Ms Danley:** Absolutely.

**Mr Marchese:** You probably have seen a number of abuses that have touched you and others close to you. That's why I think you're saying we need advocacy.

**Ms Danley:** Absolutely we need it. Even in one instance when I was in a hospital with my daughter, where I'm totally capable as her guardian, she was being pushed into a case where they wanted to use her for research. The doctor, talking to me, a capable person, slipped this through under another name, and only through investigation did I find out it was a drug I'd already told him that she should not be having. He tried to slip that through me as a capable person. Well, what about somebody who isn't? What about somebody who doesn't understand or doesn't have these rights or doesn't have someone to speak for them? I will speak, but a lot of other people are intimidated by law, intimidated by medicine, and they're told, "Just leave it up to us." My experience and that of many of those I represent is that that is dangerous, dangerous, dangerous.

**Mr Marchese:** A few other quick things, just to agree: The previous speaker talked about how family members may not know how to advocate or may be afraid to act, for fear of reprisals against the resident. Others say, "If we don't have right of entry, we have no authority to be able to correct where there are abuses."

**Mrs Boyd:** I want to thank you for quoting the Charter of Rights and Freedoms to us. It's very interesting that none of the legal professionals has actually done that. I think it's very important that we know that for consumers that charter is the watchword and the measure against which we measure justice in the country. I think you have pointed out exactly why so many of the groups that have come before us from the consumer point of view have said that this legislation will be challenged, and they are very clear about why it will be challenged. So I think it's a very good lesson to us that we need to listen to consumers. It's not surprising to me—it won't be surprising to you—that it's the professionals who have objected to the Advocacy Act; it's the professionals who have objected to rights advice; it's the professionals who have objected to all of those things that you've talked about that try to balance the power between the person who's at the mercy of the health care professions and the health care professionals themselves.

**Ms Danley:** It's been my experience too that any professional who operates truly professionally isn't bothered by an advocate at all. My experience has been it's only those with hidden agendas; the more hidden the agenda, the more they are against having someone speak on someone else's behalf.

**Mrs Boyd:** In fairness, we heard that too.

**Mr Parker:** Thank you very much for appearing before us this morning and assisting us with your views. Frankly, just to pick up on that last point, the message I take from the fact that the legal people who have appeared before us have not raised the Charter of Rights as a concern is that they don't see the Charter of Rights as being violated by this legislation. I suppose, if your message is anything to go by, we'll be put to the test and

we'll find out in due course. But so far, that is not the message we have received from people who appear to have expertise in that field.

**Ms Danley:** May I ask you a question? How do you feel about it? Not your experts, but you as an MPP, as a person representing the public, how do you feel about the Charter of Rights and whether or not that violates it?

**Mr Parker:** I am comfortable with this bill and I do not fear a charter challenge.

Tell me something about yourself and your group. Frankly, it would be useful to me if I could put your remarks in some context, and yours is a group I'm not familiar with. You could just take a minute and fill us in on that.

1120

**Ms Danley:** Sure. As I explained in the first part of this presentation, I'm a co-founder of a group that started a few years ago called the Survivors of Medical Abuse, women who've been surgically, psychologically and sexually abused by a variety of health care practitioners. We came together to form a support advocacy group for a great need out there. We have advocated extensively with the College of Physicians and Surgeons on Bill 100, talking to legislators wherever possible, and we're a phone call in the middle of the night when a woman is in trauma because of being revictimized—and I use the College of Physicians and Surgeons because it's quite prominent—through their victimizing, slanderous tribunals, their way of discerning justice, which is as archaic and barbaric as you can get. The only difference I see with them is that today we don't burn women at the stake; we psychiatrize them and give them Prozac.

It's been my experience and my colleagues' experience that we have the same running problems, the same running themes. We're not listened to. We tell you all kinds of ways to help, all kinds of ways to make things better, and everybody is taken into consideration except the victim in all of these cases—except the victim. Even in their tribunal, a complainant has no party standing. The doctor does, but not the complainant. But she can have her medical records or psychiatric records made available for a defence counsel, a misogynistic defence counsel to rip apart and try to make out like she doesn't know the difference between a sympathetic touch and a sexual aggression. That's a very large aspect of what we're dealing with. As I said, the phone calls in the middle of the night, the trauma, the children's lives, the family lives that are affected by this; the cascading effects of this kind of immoral, twisted, distorted law.

We meet on a regular basis. We have no funding. We have tried for funding several times. The money that we use comes out of our own pockets. Somebody has to be there. We align ourselves with two or three of the other advocacy groups, the funding for one of which has been cut, and I don't know what's going to happen with them. We work alongside the Barbra Schlifer clinic. We work with NAC and Metrac and a number of the women's groups. We work together in all of this. I hope that answers your question.

**Mr Parker:** You spoke quite passionately about electric shock therapy; "cattle prods" you called it.

**Ms Danley:** Yes.



**Mr Parker:** We've heard from others on this subject. Can you just describe to us what it is?

**Ms Danley:** What do you think? Have you ever watched a western on TV. How would you feel if somebody came up to you with a prod? I don't even know what the voltage is. They touch with that. That's like being electrocuted. It's like if you put your hand on a bare wire. Your body would respond to that. Well, your brain responds, your body responds. They don't talk to you about the number of people who suffer damage from electroshock, who suffer loss of memory, who go into convulsive states. The downside of electroshock is paramount, but there are those out there who say that it works really well. Something where you're going to give massive electroshock to a body, to a brain, what, to jolt somebody out of some problem? Usually the problems are the psychiatrized diagnosed people are victims of assault in some way, they're victims of poverty, they're victims of poor legislation, they're victims because they're not being heard.

**Mrs Caplan:** Thank you very much for a very passionate presentation. Certainly I think you have everyone's attention and I think that it's important that we hear from organizations such as yours which are dealing with those, albeit I think few, in society who are truly victimized. We'd like to think that there are fewer than there actually are. We know that this legislation does not and will not, with the repeal of the Advocacy Act, as opposed to trying to fix and amend it to come up with something that is going to respond to those needs in a way that is more affordable and realistic.

You do ask a question, and that is, can't this government do anything in moderation? I think it's reasonable for you to have an answer. From my perspective, no. But I guess it's something that at least this time we have a government willing to hold these hearings extensively across the province. That was different than what they originally planned for Bill 26. Frankly, I don't think it is fair to compare this legislation to Bill 26. Bill 26 was far more extreme—and I've used the word "ominous"—in its policy implications.

**Ms Danley:** I can appreciate what you're saying. However, when you're talking to voices in the middle of the night, it certainly seems ominous to them.

**Mrs Caplan:** I don't dispute your experience.

**Ms Danley:** One other thing that I'd like to add: It would appear that there's a myth about that the people I'm talking about are few and far between or there are not that many. Let me dispel that myth here and now, loudly and clearly. There are a lot of people who do not come forward, who keep closeted, who keep quiet, who are in psychiatric prisons, who are in hospitals, who are in homes, who are pulling the covers over their heads, who are afraid to come out and talk. There are some of us who for some reason are able to, but there are many who don't, and to think that this particular factor of society is small is not a realistic point of view.

**Mrs Caplan:** Well, I want to go on record as saying that I don't think the Advocacy Commission and approach to advocacy as it was contemplated by the previous government would have been sustainable, simply because it was unaffordable and also it was extremely

intrusive and caused a tremendous backlash from all of those who were covered by the legislation. I don't think that did a service to the vulnerable people in society.

So one of the things that I believe you have to come up with in the drafting of legislation is a mechanism that is affordable, sustainable, and something that everyone can feel is an appropriate way to proceed. Unfortunately, I think the intention of the new government to not bring in legislation, to not amend and fix this act and to rely wholly on organizations such as yourselves, is just as misguided as the previous costly and intrusive approach.

Unfortunately, I don't think that the process the new government is undergoing is going to result in something you will find acceptable, and I do believe that the cause of advocacy and the work of organizations such as yourselves and Concerned Friends, which were here before you, will be set back. I just wanted to share those thoughts with you. I really don't have any questions. There are some things in your presentation that I agree with and there are others that I don't. But that's what this is about; we're not going to always agree on everything. So I just want to thank you for your presentation.

**The Vice-Chair:** Thank you for your presentation.

JOHN DeSIPIO

**The Vice-Chair:** The next presentation will be from John DeSipio from Blake, Cassels and Graydon.

**Mr John DeSipio:** By way of introduction, I am a lawyer and, as you said, I am a partner at the firm of Blake, Cassels and Graydon, where I have practised since my call to the bar in 1974. For the past 22 years my practice has either been exclusively or substantially in the area of wills, trusts and estates. I'm currently a member of the executive committee of the estates and trusts section of the Canadian Bar Association—Ontario.

As a preliminary comment, I would like to express to you that in my view there is a fundamental lack of balance in the existing Substitute Decisions Act and that I believe Bill 19 is a very positive attempt to restore the balance between the rights of an individual to make choices respecting the management of his or her financial assets and personal care on the one hand, and the need to protect vulnerable persons on the other hand.

I believe the current legislation reflects an erroneous assumption that a majority of persons involved with incapable persons have improper motives. The current legislation imposes numerous procedural hurdles which are designed to protect rights, but experience shows that these hurdles in fact may deter care by causing delays and confusion, intimidating families in the process.

I believe there is an unnecessary degree of complexity in the current legislation and that Bill 19 is a positive step which will remove some of the complexities and barriers which currently exist and which will encourage both families and communities to be supportive and to become involved rather than abandoning that role to the government.

1130

I'd like to make a few specific comments on various sections of Bill 19. One of the most relevant from my practice as an everyday practitioner in this area is the

"caution to witness" provisions in the current legislation, in sections 10(3) and 48(3).

I would support strongly the repeal of the witness attestation requirements for both the powers of attorney for property and powers of attorney for personal care as they are currently set out in those subsections. These provisions, which were introduced for the first time by the Substitute Decisions Act, have been interpreted by many to impose a very positive obligation on a witness to inquire into and then to satisfy himself or herself as to the capacity of the grantor to give that power of attorney. It is not clear from the wording of the current legislation that the mere absence of any belief to the contrary by the witness is sufficient. In my experience, few witnesses are prepared or indeed even qualified to make this assessment, and as a result, it is often difficult to find witnesses for a power of attorney because of the possibility of their being brought into litigation if the capacity of the grantor is ever put forth in issue. As a result of this requirement, I have been to several institutional health care facilities and financial institutions which have adopted rather rigid policies which prohibit their employees from acting as witnesses in these circumstances for these documents.

I would also note that if the existing provisions do in fact impose this positive obligation on a witness to be satisfied as to the capacity of the grantor, this calls into question the very practice followed by many practitioners of having a staff member act as a second witness to the execution of the document. In most cases, the staff member has had little or no previous contact with the grantor and cannot make the required statement as provided by the legislation. In this case, the execution becomes difficult, inconvenient and, unfortunately, often more costly.

The proposed repeal of these provisions by Bill 19, I suggest, will greatly simplify the execution of powers of attorney and will remove what is generally considered to be a very excessively onerous obligation imposed on witnesses. I would note that for execution of wills, there is no similar obligation imposed on witnesses, and in the case of wills, witnesses are not required to make this attestation which has been imposed on them by the existing Substitute Decisions Act.

I'd also comment on my experience with clients as to the child of the grantor acting as a witness to the execution of a power of attorney. The current Substitute Decisions Act provides that the child shall not act as a witness to the execution of his or her parent's power of attorney. I would note that there was no such prohibition at law before the Substitute Decisions Act was proclaimed on April 3, 1995; in fact, practice was in many instances that a child would have acted as a witness to the parent's execution of the power of attorney.

I am not aware of any evidence that the addition of this prohibition by the current legislation has reduced any perceived abuse. I think it is obvious that a child or any other person intent on the fraud of a vulnerable person will not be deterred by the need to arrange two other people to act as witnesses. I would suggest that a child should not automatically be disqualified because of a potential conflict position with respect to an inheritance from the grantor.

I would note very strongly that there is no prohibition on a child being the attorney appointed by the parent. The appointment of the child as attorney is obviously a much more powerful position than that of merely acting as a witness and a position far more capable of being abused. I suggest that no one would argue that a child should be prohibited from acting as the attorney for his or her parent. In my view, it would follow that they also should not be excluded from acting as a witness to the execution of a power of attorney by that parent. Unlike a will, a power of attorney deals with the management of the grantor's property and not the ultimate disposition of that property. A witness will not benefit from the power of attorney unless there is a fraud.

It's apparent that there is a tremendous need for all people, not just the elderly, to plan their affairs ahead of time, and I believe the current prohibition on a child acting as a witness acts as a deterrent to giving effect to such plans in many instances. Often the client is elderly, a shut-in or hospitalized and there are practical, everyday difficulties in arranging for people outside the family to act as witnesses, especially if the client is out of the city or in another remote area.

I believe the restriction which prevents a child of a grantor from acting as a witness to the execution of the power of attorney adds nothing to the safeguards that the legislation attempts to put in place for the benefit of the grantors. It's naïve to think the legislation can be drafted in such a way as to address all variety of potential conflicts of interest or potential for abuse, which could exist with any witness. My experience is that clients are frustrated and upset that their son or their daughter is currently prohibited from acting as a witness to the execution of the power of attorney, and our clients would universally welcome this amendment.

There has been some discussion, I understand, as to the possibility of imposing a requirement that a witness to a power of attorney execute an affidavit of execution, similar to that affidavit which is required for the execution of a will. Again, I would strongly discourage this requirement. The government has expressed an intention to simplify, rather than complicate, the process of executing a power of attorney, and to promote advance planning and not to deter it.

I believe that any requirement to obtain an affidavit of execution would not prevent coercion or fraud but would clearly complicate and delay the process and possibly even frustrate the execution of a power of attorney in some circumstances. I believe it would necessarily involve lawyers and an additional cost which would not otherwise be in place. Neither this nor any previous government has required an affidavit of execution for a power of attorney. I would not support any amendment to introduce this further complication, further delay and further cost which I believe would be necessarily associated with this change.

On the statutory guardianship of property, our clients would strongly support the repeal and replacement of the provisions of sections 16 and 17 of the current legislation. Clients are universally critical of the current procedure whereby the public guardian and trustee automatically becomes a statutory guardian for property in respect



of an incapable person upon the issuance of the certificate of incapacity by the assessor, notwithstanding that the incapable person has previously given a power of attorney for property, frequently in the case of a spouse or child. Involvement of the public guardian and trustee in a person's affairs under such circumstances is viewed universally by clients as an infringement on their right of choice.

Bill 19 proposes a much less intrusive procedure by which statutory guardianship will be immediately terminated if the incapable person's attorney for property, under a continuing power of attorney for property, files a copy of the power of attorney with the public guardian and trustee, along with a signed undertaking to act in accordance with the power of attorney. This amendment will greatly simplify the procedure the attorney must follow to replace the public guardian and trustee as a statutory guardian and to commence or resume exercising the authority which was specifically given to the attorney by the grantor. If there is a concern that the public guardian and trustee needs to be able to step in where the power of attorney is being abused, I suggest that the Substitute Decisions Act has other remedies that will permit this. The public guardian and trustee has the powers to apply to court or to conduct an investigation of any such allegation under the current legislation.

**1140**

Bill 19 also proposes to expand the category of persons who can apply to replace the public guardian and trustee as the incapable person's statutory guardian of property. I would strongly support these changes, which would allow any relative of the incapable person, and not just the immediate family; the incapable person's attorney, under a limited power of attorney; or a trust company nominated by the incapable person's spouse or partner to replace the public guardian and trustee as a statutory guardian. These changes will facilitate the replacement of the public guardian and trustee and avoid the expense of a more costly court process to remove the government officials.

Bill 19 also proposes a change with respect to the mandatory requirement of security where a private applicant has applied to replace the public guardian and trustee. The current legislation provides that an application to replace the PGT as statutory guardian "shall" be accompanied by security. We would strongly support changes in Bill 19 which introduce a discretion with respect to the statutory requirements. It is obvious that it may be appropriate, given the particular facts of an individual case, that security in certain circumstances should be dispensed with, or, in the alternative, the amount of security should be released.

I understand that some bonding companies are currently having difficulty negotiating the appropriate form of bond satisfactory to the public guardian and trustee and are, in certain circumstances, unwilling to issue bonds without cancellation clauses, to which the public guardian and trustee has objected. To the extent that the proposed change gives the court more discretion, we support the changes that Bill 19 introduces for increased flexibility.

Court applications for guardianship: The changes suggested by Bill 19 again would be strongly supported.

Experience is very clear that clients are universally critical of what they perceive to be the government's interference with their personal affairs. Bill 19 is a very positive step forward, as it makes it clear that the public guardian and trustee is to be appointed as guardian only as a last resort where there is no other suitable person available and willing to be appointed.

As to the validation of the powers of attorney, I am not aware of a single instance in our office where a client has wished to proceed with a very complicated validation process. Accordingly, again I would strongly support the removal of this process. Clients are confused by it, not wanting it, and I think the changes in Bill 19 are worthy of support.

For disclosure of information, I'm aware that concern has been expressed about the potential for regulations under section 60 which will allow a doctor, for example, to give medical information about an incapable person's condition to another person, usually a child, who is applying for guardianship. I can appreciate the concern and the rationale for the concern, and I understand that the government is proposing to review and tighten up the language to ensure that the issue of confidentiality is protected, and this I would agree with. However, I wish to describe in real, practical terms the issues which make, in my view, this kind of authorization necessary.

The most typical application to court is for guardianship from an adult child whose parent has developed dementia and needs protection. Usually, there are doctors who have provided care for some time and who support the need to help the patient through the protection of guardianship. The doctors have this medical information confirming the patient's mental incapacity, but how does that information get to the court? The incapable person can't consent, even though they probably would if they could do so. To go to court in advance to obtain this consent to disclosure would obviously be a very costly and in my view unnecessary step. What happens in practice now? Doctors provide this information because there is really no option. However, they often express concern about their legal status in doing so. This regulation will bring some structure to the practice.

Overall, I believe that Bill 19 is a very positive step and will help those of us who practise in this area on an everyday basis overcome some of the difficulties. The Substitute Decisions Act is legislation which has evoked much comment among our clients. It is an area that is very personal to them. It is an area where they think they should be able to have a piece of paper whereby they appoint somebody to deal with their affairs, whereby they keep out those they perceive to be government officials, and I think that process should be as simple and as inexpensive as possible.

I believe the changes effected on April 3, 1995, gave the process much complexity and caused clients great concern, and I believe the position of Bill 19 is a step to help address those concerns and to have clients arrange their affairs in the manner they think they, rather than some other person, should be able to do, and in as simple and as inexpensive a process as possible. Thank you.

**Mr Parker:** Mr DeSipio, thank you very much for coming before us today and for assisting us with your

obviously very carefully thought out and well-presented remarks. It is nice to have the support of someone knowledgeable and well schooled in the field. Your remarks before this committee carry great weight.

My friend on the other side, Mr Marchese, has been having a lot of fun with us by anticipating our remarks in response to some of the other presenters, and I'm going to see if I can play his game.

He's inclined to take the view that it's all well and good to streamline the procedures for the mainstream, for the well-to-do, for the people who are capable of taking care of themselves, but that as a government we've got to look after the vulnerable, the weak, the infirm, those who don't come from happy families that look after one another, those on the fringes who need the protection of extra legislation. He has been critical of this bill in that respect. Do you have a response to give to an argument of that nature?

**Mr DeSipio:** I'm certainly aware that the potential for abuse exists whether it's in wills or powers of attorney. My belief is that the provisions of the current legislation do not overcome those situations where there is going to be an abuse, where there's going to be a plan, something carried out. In fact, what happens on an everyday basis with clients is that there are difficulties and hurdles to overcome, and my conclusion would be that there are far more cases where the correct thing isn't accomplished because of the provisions of the current legislation than the rare case where the current legislation might protect an abuse. The attestation of witnesses, currently in the legislation, is an everyday practical problem for us. It's not in for wills, and I'm not sure that those who would suggest it be retained will be able to convince me that there is a benefit there that would outweigh the advantages of removing it.

1150

Powers of attorney should not be something available to those who go to big firms, who are wealthy, who are sufficiently intelligent or schooled. The government's intention has been to get this document out to everybody, that everybody should be able to have a power of attorney and to plan their affairs. My experience is that in a lot of situations, the child is the one who is most able to look after the elderly person, that it is a close-knit family, that one child might be the attorney, the other children might witness the attorney. In fact, with a safeguard whereby you make that person who only has family members try to get other people to come to witness a document, what you're going to end up doing in many cases is depriving that person of the actual document which is going to protect them.

There is no question that whether it be a power of attorney or a will, there is potential for abuse. I suggest the current provisions don't eliminate that but impose more hurdles, and clearly the legislation provides a mechanism whereby if there is an allegation of abuse, there can be an investigation conducted and the remedies brought before the court.

**Mrs Caplan:** I agree with the statement you made that access to powers of attorney should be as simple as possible and as inexpensive as possible. I always advise constituents and anyone who asks me that if they have

substantial assets, they should have a will, they should have a power of attorney and they should see a lawyer.

**Mr DeSipio:** And I wouldn't restrict it to those who have substantial assets. I think they should all have a will, a power of attorney.

**Mrs Caplan:** For those who don't have substantial assets, I tell them they should have a will and a power of attorney, but they don't necessarily have to see a lawyer. Would you agree with that?

**Mr DeSipio:** I agree, and even those with substantial assets. It should not necessarily be only for lawyers to provide this kind of advice. Death and growing old are inevitable, and it should be something that everybody thinks about. If you have some wishes either to dispose of your property during your lifetime, on death, or to appoint somebody to care for that property during your lifetime, that should be an inherent right of everybody.

**Mrs Caplan:** I agree with that. I have some concerns, however, because the power of attorney for personal care is a new concept and people are just beginning to understand it. It is very different from a will.

**Mr DeSipio:** Correct.

**Mrs Caplan:** Most people don't realize that a power of attorney ends on your death and that's when your will takes over; therefore, you may want to have something different in your power of attorney or you may want the same thing, but you should think about that. The difference of a power of attorney for personal care is that the people you choose to make decisions for you could well be the people who will be heirs under your will. That could lead to abuse, as you mentioned, and that's one of the new features here.

While there are some safeguards around the obligation of the caregivers if they don't think the substitutes are acting in the best interests, and I agree with that, I've always felt it was not an unreasonable safeguard, and it was quite easy for those who went to big law firms, to have someone else there do the witnessing and for others to have either friends or neighbours or other family members.

But rather than getting into the prohibition against children, maybe the way to do it is to have a clause in the legislation that would deal with those who would have a financial interest as an heir under a will, if they have knowledge of that, or anyone witnessing, just as there's a prohibition against the attorney to witness. I wonder if you've given that any thought as a different concept that tries to anticipate the potential conflict which would lead to the abuses you mentioned.

**Mr DeSipio:** It is perhaps a possibility. I haven't addressed it specifically. I note your comment when you say it's easy for those who go to the big firms to get the second witness and the power of attorney. Again, I have problems with that. We bring a second person in from the office, very often a secretary, who is asked to sign this attestation. She's not comfortable with it. We're not sure this is the appropriate statement she can make. Is she supposed to sit down and make a positive inquiry into the capacity of the donor?

**Mrs Caplan:** There's no longer an obligation to do that. All you do now is witness the signature.



**Mr DeSipio:** Correct. That's what I suggest should be done, and that's great, as Bill 19 proposes to eliminate it.

**Mrs Caplan:** I agree. With that gone, you're only witnessing the signature; therefore, she wouldn't have any problem with that.

**Mr DeSipio:** Not at all.

**Mr Marchese:** Mr DeSipio, I want to spend a moment to tell you why I disagree with you on some general statements you made and then ask you a question or two on some other areas.

First of all, I disagree with you and the government and Ms Caplan as well with respect to your views about the commission and the Advocacy Act. When you say the bill restores rights to make choices re personal care and the need to protect vulnerable people, many people disagree with that. We don't think it does that, and that repealing the Advocacy Act, which contains in it the right of entry to deal with issues of neglect, exploitation and abuse, and to eliminate the rights advisers who would give advice to people who otherwise would not be getting it, is a serious deficiency. To eliminate the commission, which Ms Caplan also supports, which provides training, education, community development and work in areas of systemic abuse is a serious deficiency, something I believe the government needs to be involved in. I'm not sure we're restoring that balance at all. In fact, we are imbalancing it once again. That's my general comment on your initial remarks.

With respect to witness provisions and repeal of the witness statement, a number of people, quite a number, in fact, state that it is an important obligation to impose on the person witnessing it and is not an undue kind of imposition. You're saying that legalistically it sounds like it's too much of an imposition on people, but a number of people see that as a positive thing, as a reminder to those who are witnessing that this is a serious matter. How do we balance that interest? Do you have any other suggestions? Would the wording, for example, "a person who believes on reasonable grounds that," any kind of wording like that, provide some protection to a vulnerable individual or no?

**Mr DeSipio:** My position would be that there should be no statement required by the witness at the time of execution of the document. In my view, a will is a far more fundamentally important document—it's disposing of property—and we have no similar obligation with respect to the execution of a will. The common law hasn't imposed that obligation.

My experience is in going to visit clients, not necessarily all Bay Street clients, but a lot of elderly people—hospitals; I was there last week with my secretary. It is very difficult to explain to a witness: "I would like you to sign this statement." What is "on a reasonable basis"? I appreciate the concern that maybe we could modify the language. It's just very difficult to get a witness brought in, whether it's my staff or somebody else at a health care facility or wherever, and get them to sign with what they perceive to be an obligation. If you deny the person who wants to sign the document because nobody else will witness it, that to me is a far greater disservice. I would rather err on the side of having the document in place and then having it perhaps questioned or challenged than to deny the person who wants the will or the power of

attorney put in place because I can't get a second person who is comfortable making this statement or a reduced statement or another watered-down version. Clearly a watered-down would be better than that which is imposed on the witness now, but I still am concerned that it wouldn't be enough and I would rather have the document signed and let those who allege an impropriety allege it.

**1200**

**The Chair:** Thank you, sir, for giving us your expertise in regard to this bill.

Could I have five minutes of the committee's time? First, Susan Swift has obtained for us the head note of the case that was referred to the other day, "Richard B." If someone is interested, I'll deposit that with the clerk and you can obtain that from her.

I raised two matters, and Mrs Boyd wants to discuss them, the first being the potential amendments by Thursday. The standing orders, I'm advised by the clerk, provide that the amendments should be presented two hours before clause-by-clause begins, but there's some flexibility; that is not ironclad. I thought when I made the suggestion that we would have the amendments to review over the weekend.

**Mrs Boyd:** It's not that we disagree, Mr Chair, but we had no sense of whether everybody has agreed to this. If we all agree to that and put on the record that we all agree to that and make a commitment that by the end of Thursday we all will have everybody's amendments, that's fine. Normally, at least in my experience, caucuses sometimes want to say, "Yes, to the extent possible, but we still reserve the right, two hours before, if there's a change." It's not that I disagree. It's just that you dropped this into the middle of the room and there was no discussion and we had no sense of whether there was a commitment on all sides.

**Mr Michael A. Brown (Algoma-Manitoulin):** We certainly would appreciate having the amendments on Thursday. It would be very helpful to us. We cannot possibly say that we will have them all ready. We would hope that would be the case, but some of this obviously has to go to legal counsel to be drawn up and what not. It's of benefit to all members to have those available, but we obviously don't believe we should be restricted from further amendments if that's the case.

**The Chair:** I don't think we're trying to preclude. We're just trying to expedite.

**Mr Michael Brown:** Then certainly we would find that to be helpful.

**Mr Parker:** I think we can proceed with a "reasonable best efforts" understanding attached to your submission. We just do our best, and if something comes up late, it comes up late.

**The Chair:** The second point I raised is that the Chairman of the finance committee had requested that we remain in this room, although we were scheduled to move into the Amethyst Room next week for clause-by-clause. I take it they are considering the automobile draft bill, which is of wide public interest, and that was the reason for it. I request your instructions.

**Mrs Boyd:** Mr Chair, we have a question about that, given that we all have agreed here that far greater public

education is required around the issues under these acts. I'm not sure it's in the best public interest that it not be accessible, particularly to disabled people who may be in their homes and may be able to see it. We certainly know from the presentations before us that from the first week, when we were televised, a lot of the people who subsequently presented have built their presentations on watching that.

Is this the only week the automobile insurance thing will be proposed, and is it clause-by-clause?

**The Chair:** I can't help you there, Mrs Boyd.

**Mr Michael Brown:** If my understanding is correct, they will be dealing with the automobile insurance issues. We have no objection to having the finance committee remain in the Amethyst Room. We believe we can go through the clause-by-clause here in an appropriate way.

**Clerk of the Committee (Ms Donna Bryce):** If I could clarify, the request to switch rooms was for this one week only. I believe we are scheduled to be in 151 again next week. If the committee wants to change that, I think the Chair had suggested that we remain here just for convenience and no other purpose.

**The Chair:** If there is an objection, we won't do it.

**Mrs Boyd:** I don't want to be difficult. Mr Chair, I want you to know that I would feel very sad if, because we were on television, we behaved differently than we have been behaving. I think it's really important that we have a clarity about our commitment to try to make this bill work as well as possible and that it not be a case for grandstanding. That's not the reason for my suggestion. If there is no good reason for us not to be in the room we were scheduled to be in, I think it would be foolish for us not to be there.

**Mr Parker:** I think in all of this we have to be mindful of the people we serve, and if there's one message I received loud and clear through the election, it's that there is a great deal of concern and apprehension about auto insurance in this province—has been for many years. It's been the high-water mark of some parties' campaigns in the past.

**The Chair:** Mr Parker, I inadvertently misled you. It would seem that the room is vacant, so please do not use that as a consideration.

**Mr Marchese:** Next week it's vacant?

**The Chair:** Yes. So it's a matter of staying here or moving into a vacant room.

**Mr Michael Brown:** Could you help me in understanding how the schedule is arrived at in the first place for who goes where?

**The Chair:** The clerks scheduled us in room 151 on the basis that this is of some interest to those who have certain disabilities and that perhaps they would be watching TV and would be educated. That's an understandable premise. If you feel you wish to remain in 151, then we shall. Okay? Thank you.

*The committee recessed from 1207 to 1332.*

#### UNIVERSITY OF TORONTO

**The Chair:** Our first submission is made by the University of Toronto Joint Centre for Bioethics, Dr Singer and Dr Etchells.

**Dr Peter Singer:** It's a pleasure to be here with you. My name is Peter Singer. I'm the director of the University of Toronto Joint Centre for Bioethics. My colleague Ed Etchells is a member of the department of medicine at the University of Toronto and the Toronto Hospital.

I understand that one of the main issues that's arisen in these hearings has been the question of rights advice. This is the issue I'd like to focus on in this presentation.

Much important streamlining has been accomplished in the change from the Consent to Treatment Act to the Health Care Consent Act. The single largest change is the elimination of rights advice. I think this is a positive change. However, I can understand how your committee might be concerned about the elimination of rights advice and so I wish to explore this with you today.

My bottom line is this: Protecting the right of citizens to make their own health care decisions is extremely important. Legislated rights advice is the least effective means of achieving this goal and might actually be counterproductive.

I just want to make it very clear from the outset that I think these rights are very important; I think rights advice is very important. My only question is whether legislation is the appropriate vehicle for it, and I think the answer to that question is no.

What's the goal of rights advice? The goal of rights advice is to prevent capable people from being declared incapable. This is an extremely important goal. Capacity is a fundamental human rights issue. When a person is declared incapable, she no longer directs her health care decisions. The right that rights advice protects is the right to make one's own health care decisions.

How can the right of capable persons to make health care decisions be protected? There are at least four tools that can be used to protect the right of capable people to make their own health care decisions: Research, education, policy and legislation. They each have an important role to play, and I'll explore them one by one.

How can research protect the right of capable people to make their own health care decisions?

The initial assessment of a person's capacity under both the consent act and the Health Care Consent Act is done by health providers. I'd submit that the best way to ensure that capable people are not deemed incapable is to ensure that health providers assess capacity as accurately as possible. In this regard, my colleague Ed Etchells has made major research advances, I think, in developing a decisional aid to help health providers assess capacity accurately, and I'll now ask him to describe this research for you.

**Dr Ed Etchells:** We've developed and evaluated the aid to capacity evaluation and we've assessed its accuracy with regard to health providers' assessments of capacity. The ACE, which we've handed out, prompts health providers to assess the relevant domains of capacity. I'd just like to take you through it briefly.

On the first page are instructions to the health care provider on administering the ACE. On the next page are instructions for scoring, and then the next three pages are some samples for scoring. We train the physicians by exposing them to a standardized patient portraying a depressed person refusing surgery for gangrene. Subse-



quently are the scoring sheets for their actual patient when they assess their capacity. It prompts them to probe the seven relevant areas of capacity assessment and we give them space to mark down evidence or observations that support their assessment in each of the seven domains. On the next page the clinician is asked to give an overall impression, make any comments including indications for further assessment as they're required, and on the back are just some useful questions to guide the clinicians for probing each of the relevant domains.

We compared the results of health providers' assessments to the results of capacity assessments by two independent experts. Disagreements between the two experts were resolved by an independent adjudication panel. We found that ACE results of definitely capable or definitely incapable were very accurate, while results of probably capable and probably incapable were less accurate. We also found that health care providers were willing to devote the necessary effort to make the capacity assessment as fair and accurate as possible.

Our results suggest that health providers can accurately perform screening assessments of capacity using standardized instruments, such as the ACE. If the result of the assessment is definitely capable, then no further assessments are needed. If the result is probably capable or probably incapable, further in-depth assessments should be obtained.

**Dr Singer:** The next question is: How can education, the second of the available tools, protect the right of capable people to make their own health care decisions?

Since the initial assessment of capacity is made by health providers, it's extremely important that providers understand the human rights issues at stake and know how to assess capacity accurately. I'm glad to say we're making progress in this regard.

For instance, the Royal College of Physicians and Surgeons of Canada and the College of Family Physicians of Canada—and I'm using medical examples of health providers because those are the ones I'm familiar with; I'm sure that analogues exist in other areas of health provision—organizations that accredit teaching programs for all specialists and family physicians in Canada, require ethics training as a condition of accreditation of these programs.

At the royal college, the bioethics committee has undertaken a project entitled the bioethics education project. The purpose of this project is to integrate bioethical knowledge and skills into the clinical practice of resident physicians enrolled in royal-college-accredited programs.

As part of this project, we've developed a teaching module on capacity. The module focuses on the human rights issues related to capacity, as well as the definition of capacity and how to assess it. We'll be distributing the aid to capacity evaluation Dr Etchells just showed you and walked you through and teaching resident physicians how to use it.

The next available tool is policy. How can policy protect the right of capable people to make their own health care decisions?

Rights advice is an area where health facilities can enact policies to guide practice. Two weeks or so ago, you heard Dr Alan Goldbloom from the Hospital for Sick

Children speaking of developing rights advice policies and this Thursday you'll hear from Ms Margaret Keatings and Dr Neil Lazar from the Toronto Hospital about this issue as well. In addition to health care facilities, the professional colleges can develop policies on rights advice. Indeed, if necessary, under the Regulated Health Professions Act, the Minister of Health could require the colleges to do so. Policies are more flexible than legislation. Rights advice policies, as opposed to legislation, permit the development of varied approaches appropriate to each setting and sensitive to patient needs.

How can legislation, the fourth tool I mentioned, protect the right of capable people to make their own health care decisions?

The Health Care Consent Act, as did the Consent to Treatment Act, contains several important provisions with regard to protecting the rights of capable people to make their own health care decisions. It defines capacity in a very sensible way. It also creates the Consent and Capacity Board to review determinations of capacity.

But why should the Health Care Consent Act not include provisions for rights advice? I will not discuss the issue of third-party rights advisers since I believe this is not currently under consideration. Rather, I'll focus on why I believe it's inadvisable to include legislative provisions mandating rights advice on the part of health providers. I'll also not read into the record the recommended statement, "Notice of rights in other places under subsection 9(3) of the Consent to Treatment Act," because I believe others have done so and I suspect that most of you are probably convinced by now that language like that, which, to be fair, was recommended but not required language, is inappropriate in the context of a caring relationship between health provider and patient.

**1340**

However, you're probably wondering whether there should not be some legislative provision about rights advice, perhaps leaving the exact language to the discretion of health providers. I argue that there should not be rights advice provisions in legislation and offer the following reasons:

Rights advice provisions are very likely to be ineffective. The rights advice provisions of the Consent to Treatment Act have been largely ignored. There's no reason to believe that rights advice provisions in the Health Care Consent Act would be followed. The options for government then, as a practical matter, will be either to mount a massive and expensive enforcement campaign with regard to rights advice or to permit rights advice to be devalued by non-enforcement of explicit legislative provisions.

Alternatives to legislation, such as dissemination of an instrument like the aid to capacity evaluation, provider education regarding capacity and policymaking by health facilities and professional regulatory bodies, are, I believe, likely to be effective at protecting the important rights at stake.

In contrast to issues like disclosure, there is very little experience or common law on just exactly what the conversation between a health provider and patient should look like just after the health provider has assessed the patient and found her to be incapable with respect to consent to treatment. There are no accepted standards for



rights advice. It is premature, I believe, to legislate something so unclear and so untested.

If the legislative rights advice provisions are specific, they will create the same problems encountered with the recommended statement in the Consent to Treatment Act. That is, they will either be ignored or followed in a legalistic and bureaucratic manner that erodes the caring relationship between provider and patient.

On the other hand, if the legislative provisions regarding rights advice are left vague, they will unfairly expose providers to liability for not following some oblique and unspecified legislative duty.

After the justifiably negative reception of the Consent to Treatment Act, providers will be hostile towards legislated rights advice. The message regarding the importance of rights advice should come from opinion leaders within the health care professions and from the professional colleges, because that's the way the message I think is most likely to change provider behaviour, which is the goal.

Sometimes rights advice may even be harmful by rubbing people's noses in the fact of their incapacity. Legislation does not provide sufficient flexibility for cases such as this.

Ontario is the only jurisdiction in the world I've been able to identify that has provisions in effect for rights advice in the non-psychiatric setting. Not including rights advice provisions in the Health Care Consent Act would bring Ontario law into conformity with the law in the rest of the world.

Philosophically, legislated rights advice is an inappropriate, I believe, intrusion of government into a private sphere relationship between health provider and patient. I don't think the government should be in the business of mandating the speech of private citizens.

There is another situation in both the consent act and the Health Care Consent Act where the government does in fact mandate speech, and that's a useful counterpoint. That's the issue of the standards of disclosure, but there's 20 or 30 years of experience on standards of disclosure, what they should be, much common law, including the Supreme Court of Canada case in Reibl and Hughes. I think that in a situation like that, government-mandated speech may be appropriate, but in a situation like rights advice where the standards are completely unclear, I believe at this time it's an inappropriate intrusion.

In summary, protecting the rights of citizens to make their own health care decisions is extremely important. I believe this goal is best served by not legislating rights advice. If there's one lesson from the untoward experiences with the Consent to Treatment Act, this is it.

If I might just say, the Consent to Treatment Act and Health Care Consent Act both contain excellent provisions for guiding clinical practice. You've heard my preference for the Health Care Consent Act, but 90% of what's in both of them is very helpful in terms of educating providers and in terms of providing a foundation on which to build. I believe that the negative reaction on the part of providers to the Consent to Treatment Act was narrowly related to that 5% or so that dealt with provisions related to rights advice, and I think one ought to be very careful before reintroducing legislative provisions related to rights advice. The right itself is extremely

important to protect. Rights advice itself is important. The appropriate vehicle, however, for rights advice and for protecting these rights is not legislated rights advice reintroduced into the Health Care Consent Act.

Thank you. I look forward to your questions.

**Mrs Caplan:** Thank you very much, Dr Singer. I'm an admirer of your work, and I would like to discuss with you some options that might be acceptable.

Personally, I believe there must be an obligation to communicate. I don't think the law should be prescriptive as to what the communication should be. In fact, I would be perfectly happy if the colleges were able to establish those guidelines. However, under this legislation we've heard that social workers and others who are not regulated professionals can be empowered evaluators by regulation.

Therefore, I would be content—and I'd like your opinion on this idea—if this legislation said that there's an obligation to communicate, and I wouldn't use the words "finding of incapacity." What I would say is that where an evaluator determines that an individual is unable to understand or appreciate the consequences of a proposed treatment, and where there is a college, it will establish the guidelines for how that can be done appropriately, and where there is not, then by regulation—and hopefully they would decide to prescribe the use of this as the tool, so that you would have a communication that was consistent. I think this is an excellent tool. This ACE is what I'm referring to.

Something as simple as that I think might solve the concerns of those who have come before the committee to say, "You can't remove all of the obligation to tell someone when they have been found incapable at the same time as you are removing all liability of the provider who provides the treatment, and you're also removing all liability of the substitute who is called in." Certainly as an ethicist you have to have some concerns about no liability and no need to inform.

**Dr Singer:** I think you've really provided the sharp and difficult and narrow question, which is not related to third-party rights advisers. It's not related to recommended statements. It's related to legislative provisions which just saw off very soon, in terms of providing some duty to communicate.

I've thought about this a lot. If this were 1993, I would probably say, "That sounds like a great idea; it should be included in legislation," because in theory it's not such a bad idea. However, given the practical history of what's happened with the Consent to Treatment Act, my advice would be not to include legislative provisions no matter how watered down because of the various arguments that I've given in terms of bullet points.

Having said that, communication is extremely important, and I spend much of my professional career trying to establish ways to communicate around advance care planning, advance directives, living wills, powers of attorney for personal care. But increasingly I believe that on the one hand such communication can't be stimulated by legislation—and we actually have examples in the advance care planning area in the patients' self-determination act in the United States, which really hasn't stimulated communication—and on the other hand, legislative attempts to do so may be counterproductive.



So whereas I completely agree with the goal of communication, I think legislation is ineffective and possibly counterproductive in getting to that goal, and some of the other strategies in professional education, in some of the research transfer activities and some of the policy activities that I've suggested would be more effective in reaching that goal, which we both share.

**Mrs Caplan:** Well, then, how do you feel about the notion of absolute liability for proceeding with a treatment in the absence of the communication?

**Dr Singer:** I'm not a lawyer, so this is a layperson's view on liability issues, but I think there are a lot of requirements that are totally justifiable related to disclosure, for instance, which is itself an act of communication in the consent act, and I would be extremely uncomfortable if the disclosure requirements were not in a consent act. So I think communication is important. There are a number of legislative provisions in the Health Care Consent Act that stimulate communication.

1350

The one narrow piece of communication that's not currently in the Health Care Consent Act is, what do I say as a provider after I've found someone incapable? Should I have a legislated duty to say something like: "I've found you incapable. You have the right to appeal"? After much reflection, my answer to that question for the reasons I outlined is that I think it's inadvisable to have a legislated duty. I think in most cases I should do that; in most cases I do do that. In terms of stimulating my colleagues to do it, I think the most effective way to do that would not be to reintroduce legislative provisions related to rights advice into the Health Care Consent Act but rather to follow these alternatives.

Moreover, as a liability issue, if it is sort of a watered-down rights advice provision without specifying how that will occur, I'd like to hear some legal advice about holding physicians to a standard of liability with regard to consent for this oblique duty which has not been characterized. On the other side, I don't think that would be a fair liability situation for physicians or other health providers.

**Mrs Boyd:** Thank you, first of all, for your presentation. It was very helpful and I must say that this ACE evaluation scheme and the way in which you've set it up is very, very helpful in terms of helping people to know how this evaluation would be done.

I'm very surprised to hear someone with your reputation, and I agree with Mrs Caplan that certainly it's a very fine reputation in terms of bioethics, come forward with the strength of this advice that you have given. It's not unusual for us to hear it; we hear it from health care providers all the time. It's the consumers who don't seem to be balanced in this whole issue.

If health care providers had been providing advice and information to patients all along, there would never have been any need for this legislation in the first place. This arose because of the many horror stories and the fact that people were being treated without their consent, without their knowledge, without full disclosure. That's why we are here today, and one of the reasons we are here is hearing again and again from consumer groups that this didn't end in 1993 at all.

The resistance that the medical profession showed to any effort on the part of any government to call them to be accountable for this sort of thing is the very reason that you're suggesting we shouldn't legislate? In other words, if people behave badly and refuse to obey legislation, they get rewarded by having that requirement withdrawn? I'm amazed. It doesn't sound like you at all, if I may say so. I think you're right. I think you would provide that information and that advice. The problem is many of your colleagues don't.

It really worries me that you are presenting this committee with "You can't do any of these things and you have to trust the very people who, although this has been brought to their attention again and again, as colleges, as education facilities, as professional associations," and we're supposed to just leave it up to them to do what they have never done and what we hear terrific resistance to doing? I think that would be very irresponsible of us as people who have a fiduciary responsibility to protect the vulnerable in society.

**Dr Singer:** We come at many of the issues the same way, but some of the issues differently. I am not suggesting that consent ought not to be legislated—standards of disclosure, standards of capacity. It's a very narrow thing related to rights advice. I'm also not suggesting that the right itself—and narrowly it's a capable person being declared incapable unjustifiably—I'm not saying that's a good thing; that's a terrible thing, and I characterized it as an abuse of human rights. I'm also not suggesting that rights advice is not important. I think rights advice is important.

Reasonable people will disagree about this narrow question and I don't think taking one side or the other would call anyone's reputation into question on this narrow point. The only question I'm asking is whether the goal of protecting rights, and in particular rights advice, and making sure capable people are not declared incapable unjustifiably, is best served by having a provision in the Health Care Consent Act mandating rights advice.

The answer to that question is no. Fundamentally, part of the problem, and it's a very narrow thing—

**Mrs Boyd:** But if it isn't and you're saved from liability and there's no more Advocacy Commission, what recourse does the person have? None. There is absolutely no recourse under those circumstances. You're safe, not liable, there's no Advocacy Commission, there's no protection for the individual.

**Dr Singer:** Again, I'm not a lawyer, but I would think that a couple of places that person would have recourse would be to the Consent and Capacity Board, would be to the courts. Those structures are still there, so the forums for recourse are there.

**Mrs Boyd:** They don't know about it.

**Mr Marchese:** How would they get there? If people don't know about their rights, how do they get to the consent board?

**Dr Singer:** I think to assume that just because you don't have a legislative provision about rights advice means that people won't know about their rights is an awfully big jump. I'm suggesting several alternative

avenues towards protecting the right in general and towards fostering rights advice in particular. Let me make it clear again. Consent is important. These rights are extremely important. I devote my professional life to trying to protect them. Capacity is extremely important, and to declare someone incapable unjustifiably is a fundamental deprivation of their human rights. Appeal mechanisms should be available. Rights advice is important.

My narrow question is: Does it best serve the goal of protecting these rights to prevent incapable people from being declared incapable unjustifiably, fostering rights advice and promoting these important rights that we hold dear, is that best served by legislative provisions or alternative mechanisms to pursue the rights advice? My conclusion is, it's best served by not having legislative provisions.

**Mrs Johns:** I'd like to thank you for your presentation. It gives us a lot of food for thought. I believe, as you have said, that the issue we are really trying to solve here is the capable person who has been deemed to be incapable. I think we all agreed that that's the process.

What I worry about is that part of the failure, if you will, or the area that is least proven to be successful in this is the probably incapable and probably capable. Those are the two areas that we're most concerned about, and this report isn't doing the best job in those areas. Talk to me a little bit about that, if you can, and how we could try to eliminate that.

The other thing I'm concerned about that I want to talk about is, it may be well for the people who are going through your course right now, Dr Singer, and they understand what's going on. What happens with the old doc who's out there? How do we train him to be able to make sure he's doing this the way we would like to have it happen?

**Dr Etchells:** I'll address your first part, and Peter will address the second part.

You're absolutely right. I think that the issue is how do we guide clinicians to the right course of action in the uncertain middle cases, and the question—and I don't know the answer to the question—is whether rights advice would help guide them to the correct action and whether without rights advice the incorrect action would be taken. I can't answer that question.

I think that the process of doing ACE and coming to the conclusion that you're not sure is extremely valuable and actually helps clinicians recognize what the correct action is. In some cases the correct action is that they're not sure if the person's depression is affecting their decision. In that case the correct action is to have a psychiatrist come and evaluate, because psychiatrists have expertise in that setting.

It might be that the patient has a culture that is different from the physician's culture. In that setting the correct action is to find out more about the person's culture. It might be an issue of religion. In that case the correct action is to find out more about the person's religion. It might be the person's experience with illness, in which case the right course of action is further counselling and discussion before any action is taken about treatment. I think that even though you don't know what the correct answer is about capacity, the process of

doing it helps lead you to the correct action. That doesn't answer the question about rights, though.

**Dr Singer:** And on the education point, about a third of the people in Ed's study fell into that category. The screening assessments at the extremes are accurate. In the middle the screening assessments are not sufficiently accurate, and more in-depth assessments by people who have more expertise and might spend more time than the front-line health provider doing it are called for in that middle group.

With regard to the question of education, I think that aggressive efforts do need to be mounted related to consent and capacity and rights advice, and all these issues. I'd fully support and participate in these sorts of activities; in fact it sort of underlines my main point. There's a number of different tools available to achieve the goals we want to achieve and I would go so far as to say that high-quality educational programs around this issue aggressively pursued are more likely in my estimation to achieve the important human rights protection goals than rights advice provisions in legislation.

1400

**Mr Klees:** Would you say that the position you put forward is fairly representative of your profession, or is this a fairly personal view?

**Dr Singer:** That's a good question, because on the very narrow point, the way Mrs Caplan framed it, I don't know exactly what the spectrum of views is in the profession.

**Mr Klees:** If it is a widely held view, I have very serious concerns, and I'll tell you why. To see the kind of comments here that if provisions were enacted in legislation they would be ignored, that they have been largely ignored—we're being asked by you to leave this kind of rights advice requirement to your profession. If the profession's attitude is that if it's legislated, they'll ignore it, that's not a very responsible way of coming here and giving us advice about how to deal with this issue.

**Dr Singer:** Yes, and so I should be very clear. I'm not saying don't do it because it won't be followed. I'm saying if you do it, I predict it won't be followed, which doesn't justify not doing it—

**Mr Klees:** It's not a good comment here.

**Dr Singer:** Let me just finish, Mr Klees—and therefore, thinking a step or two ahead, if I'm right, you'll be in the situation where you have to do one of two things: either invest in an aggressive enforcement campaign for the rights advice narrowly, or just let it go on and be disregarded, in which case you devalue it.

I'm not arguing that the fact that it's not followed is the justification for not doing it, and Mrs Boyd made this point as well. I'm just encouraging you to think strategically. Moreover, one ought to ask why it's not followed. I think that the reason, for instance, the rights advice provisions in the consent act—my impression is that they were variably followed, let's put it like that, because most people thought, providers as well as patients and families, and this is extremely important, that that sort of language just had no role in a caring relationship, and I think most of you probably agree with that.

Now I might know and you might know that that was recommended language, but I think the average provider on the street thought, "Here's the Consent to Treatment



Act, here's this piece of legislation, here's this rights advice provision, here's this recommended form. I don't have the expertise to make up my own form. I'm going to use the recommended form," tried it out a couple of times, and families—for instance, one case I know of they laughed in the middle of this thing.

No one is arguing to reintroduce that language, but that's the way things play out in real life. I just really want to underline that you have to consider why providers didn't follow it, and it's certainly not because they're not fundamentally devoted to protecting these important human rights.

**The Chair:** Thank you, Mr Klees. Dr Singer, Dr Etchells, thank you very much for your submission today.

#### ALZHEIMER ASSOCIATION OF ONTARIO

**The Chair:** Our next submission will be the Alzheimer Association of Ontario. Welcome.

**Ms Shelley MacEachern:** Good day. My name is Shelley MacEachern and I'm president of the Alzheimer Association of Ontario.

**Mr John Ellis:** I'm John Ellis. I'm the executive director of the association.

**Ms Susan Kitchener:** I'm Susan Kitchener and I'm manager of public policy.

**Ms MacEachern:** Before I begin, I have to tell you I've flown down from Sault Ste Marie to be here today and address you, and I'm awed by this whole procedure. I've never been in the Legislative Building before and I'm quite impressed. It's really a pleasure to be here today and the responsibility that this group has to ensure that it meets the needs of the citizens of Ontario is a little overwhelming. Certainly we're very happy to be here today to offer our bit of advice to you as we see it.

We wish to thank the committee for this opportunity to comment on Bill 19. Our purpose here is to seek a balance between an individual's right to choose and the practical ability to put care and property decisions into action in a time frame which serves the individual well. We will make some recommendations to forward this purpose and will focus on the people we serve—people with Alzheimer disease and related dementias and their family caregivers.

The Alzheimer Association of Ontario is a non-profit, charitable organization of chapters in 38 municipalities throughout Ontario. Together, Alzheimer chapters have a membership in excess of 6,000 people, most of whom have been directly affected by Alzheimer disease. People who have been diagnosed as having the disease themselves are people who have or have had family members with the disease. Where individuals with Alzheimer disease or related dementias or their family caregivers ask for help, virtually all chapters assist with the advocacy for needed support and services.

The association and its chapters have an operating budget of approximately \$8.5 million, with about 27% of that amount currently coming from the government of Ontario for delivery of day programs, respite programs and counselling services. As well, chapters operate family support groups, education programs and information services for individuals, families, health care professionals and the general public.

The association is committed to providing major financial support to Alzheimer research at the University of Toronto's Centre for Research in Neurodegenerative Diseases. In addition, substantial ongoing financial support is provided to the studies of psychosocial aspects of care for people with Alzheimer disease.

Given the nature of Alzheimer disease, the existing and proposed legislation are of pivotal importance to people with the disease, their family members and friends. Getting the legislation right is critical to all of us if we are to cope with the fiscal and societal implications of Alzheimer disease and related dementias, given the projected number of Ontarians who will be directly affected by this disease.

Alzheimer disease causes a progressive and irreversible loss of mental function. It has no known cause or cure. The loss of mental function includes: progressive and irreversible loss of decision-making capabilities; progressive and irreversible loss of ability to give directions for care; progressive and irreversible memory loss; the same kind of loss of the ability to carry out functions of daily living, such as bathing, toileting, dressing, cooking, eating; loss of concentration skills, thought disorder; loss of abstract thinking skills; loss of language skills with eventual inability to communicate; loss of orientation skills, both of time and of location; loss of visual and spatial skills; progressive and irreversible loss of ability to recognize family, friends and ultimately oneself.

The progressive loss of mental function can result in a progressive loss of physical control, including: incontinence, falls, inability to walk, inability to swallow and eventual inability to function physically.

A diagnosis of Alzheimer disease marks a life of two to 15 years of steadily increased dependency requiring care, usually by a partner, followed most often by institutionalization.

Let me give you some idea about the current and projected extent of Alzheimer disease and related dementias. Health and Welfare Canada's 1994 Canadian Study of Health and Aging puts the prevalence of dementia in Ontario of people 65 years of age and older at over 90,000 individuals. It is generally accepted that Alzheimer disease represents 75% to 85% of the dementia in the elderly.

By the year 2000, the study projects that the prevalence of dementia in Canada will have increased by more than 50%. You'll notice in your brief that there's an error here, if you could make that correction.

1410

In Ontario, by 2011, when the first of the baby boom generation are turning 65, the prevalence of dementia will have increased by more than 90%. By 2021, the projection is 150% increase in the prevalence in Ontario. Increasingly, the largest group of Ontario citizens, the baby boomers, are directly affected by dementia, firstly as family caregivers for parents with dementia and secondly, as diagnostic methodology improves, Alzheimer disease is being diagnosed at earlier and earlier ages. Early-onset Alzheimer disease is just beginning to show in the baby boom generation, their spouses, partners and siblings.

For each person with dementia, it is estimated that a minimum of 10 other Ontarians are affected in trying to



provide care. Spouses, partners, children, siblings and, increasingly, grandchildren and extended family members and, of course, family, friends, neighbours and community support groups.

**Mr Ellis:** Just a few words about the existing legislation, the three acts. The association originally endorsed the intent of the existing legislation to protect the rights of vulnerable people with no supportive families or support networks. Particularly we applauded the introduction of provisions which enable people, while still capable, to set out binding decisions regarding care of their property and persons should they become incapable. We commended the codification of the common law in the requirements for consent to treatment and the introduction of the hierarchy of substitute decision-makers.

However, in deputations in 1991 and 1992 the association expressed very serious misgivings about the three acts which were then proposed. Our position at the time was steered by the structural rigidity of the rights advice process as set out in the acts. We saw the confrontation innate to the system and the bureaucracy necessitated by them as exceedingly problematic. We warned that the treatment and procedural holdups which were inherent in the rights advice process as enacted would put some people with Alzheimer disease and other dementias at risk. In fact, the day-to-day application of the legislation proved to be fraught with ever-increasing problems of complexity, cost, confusion, desperation and delay.

With regard to Bill 19, our association congratulates the drafters of the bill for listening to our growing apprehensions as the existing legislation was put into daily application. They've addressed virtually all of our major difficulties with it. The clarifications and simplified processes are indeed welcome.

We see the bill as making helpful improvements and there are a lot of them. You'll find some listed on pages 7 and 8 of our brief. So let me just outline a few for you: elimination of the day-to-day difficulties that the Advocacy Act created; removal in the Substitute Decisions Act of the onerous validation process for powers of attorney and the elimination of the requirement to file yearly plans; broadening the categories of family caregivers who can become statutory guardian; clarification of the role of the public guardian and trustee as substitute only for those who have no one else to make decisions; in the Health Care Consent Act, the maintenance of the right to appeal a finding of incapacity to the consent and capacity board.

We find particularly helpful the provisions regarding consent from family members to admissions of an incapable person to a nursing home or other care facility. The admissions process, as you will know, had become a difficulty. We like some of the concepts introduced in personal assistance services, personal assistance plans and practitioner access for consent to the hierarchy of substitutes.

We support the checks and balances offered by the provisions which allow health practitioner appeal to the consent and capacity board when they believe that a substitute decision-maker has not followed the rules of substitute consent.

On balance we support the proposed legislation. We do see some issues raised particular to the people we serve,

however, we will offer both comment and recommendations.

**Ms Kitchener:** Our purpose in making the recommendations which follow is twofold: firstly, to ensure that respect for the rights and the personal dignity of all people with Alzheimer disease and related dementias is upheld, and secondly, to ensure that as a society we keep faith with those who have made capable choices known in advance of incapacity.

We believe that most families of people with Alzheimer disease and related dementias are caring, concerned and respectful. That the changes introduced in Bill 19 take this as a starting point is a major improvement in the legislation, but where people have no supportive families or support networks, legislative provisions to protect their rights and to prevent physical, financial and mental abuse are critical.

A majority of health practitioners provide professional, suitable care, but legislation must require health care providers to seek out and abide by both the capable wishes and the decisions of responsible substitutes. We will ask for some strengthening of the legislation of this and the Health Care Consent Act.

Rights advice is the general heading for our first group of recommendations and the first of these is rights advice for findings of incapacity. The issue is this: The proposed Health Care Consent Act maintains the right of an individual to challenge a finding of incapacity to the Consent and Capacity Board. However, there is no mechanism in the act for informing individuals that they have been evaluated as incapable. The act is also silent on how a person would come to know of this finding and what the implications of the finding are, or that she or he has the option to appeal the finding.

The second issue: The Substitute Decisions Act allows the holder of a power of attorney for personal care to begin exercising that power once he believes the grantor to be incapable. It does not ask that the attorney let the grantor know that he will begin to make decisions on the grantor's behalf.

We support the principle that individuals who are about to lose their right to make personal decisions because of a finding of incapacity have the right to be advised that they are being considered incapable, that someone else will be turned to for decisions and that they have the option of appeal. For this reason we make these recommendations:

That the legislation provide that persons who are about to lose the right to decision-making be informed that this is the case, the implications of such a finding and of the right to appeal the finding and proposed outcomes.

That the legislation affirm the right of persons to receive this information whether or not it's believed that they're capable of comprehending it.

That the legislation provide that the capacity assessor, evaluator or health practitioner who makes a determination of incapacity inform the person that a substitute decider will be asked to make decisions on the person's behalf. We can talk later about how the legislation might provide that, whether it's in regulations or the legislation itself.

That the legislation provide that if a person assessed as incapable indicates an unwillingness to have substitute



decisions made on his or her behalf, the capacity assessor, evaluator or health practitioner advise the person of the right to appeal.

Lastly, that when the holder of a power of attorney for personal care is going to exercise that power because he or she now believes the grantor to be incapable, the legislation ask that the attorney let the grantor know that he's going to start making substitute decisions and why.

With regard to rights advice for admission to long-term-care facilities, the proposed legislation provides for a determination by an evaluator of the person's capacity to give or refuse informed consent to admission. Once an evaluation of incapacity is made, the person may be admitted to a care facility without his or her consent and without being told of the results of the evaluation, its implications or the right to appeal. The act maintains the right of the person to challenge a finding of incapacity but, as we noted earlier, makes no provision for informing the person.

If the recommendations which we've just made were implemented, it would provide for this kind of notice.

**Mr Ellis:** The next set of recommendations concerns the Substitute Decisions Act. Our first comments are in regard to capacity assessments.

Pivotal to the workability of any substitute decisions scheme is the efficacy of the capacity assessment process. Regulations to the current Substitute Decisions Act require the capacity assessment office, now in the office of the PGT, to train, authorize and maintain a roster of the variety of qualified legal and health professionals needed to provide assessments of capacity regarding property, treatment and personal care.

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The Health Care Consent Act introduces the evaluator who may evaluate a person's capacity to consent to admission to long-term-care facilities. While evaluators must be members of professional colleges or associations, provision is made for the addition, by regulation, of further categories.

The issues are these, in our opinion:

(1) Protecting the rights and determining the remaining ability of persons with Alzheimer disease to make decisions on their own behalf is clearly dependent on the training, judgement and experience of capacity assessors. Our concern is that changes in regulations not compromise these criteria.

We recommend that in considering regulatory changes regarding capacity assessment, the government seek comment from the Alzheimer Association of Ontario whose constituency is so directly affected by the means of determining of capacity.

(2) Regulatory additions to the categories of evaluators and assessors and/or changes to capacity assessment processes and standards may introduce the need for Alzheimer-specific training.

Our recommendation: Given its practical expertise in the development of Alzheimer-specific training curricula, that the government seek comment on training requirements for capacity evaluators and assessors from the Alzheimer Association.

Still under the general heading of the Substitute Decisions Act, we have some concerns about the potential

for conflict of interest and misuse. The association's mission statement commits it to promoting the rights and wellbeing of individuals with Alzheimer disease. In our view, two provisions in the amendments to the Substitute Decisions Act open the potential for conflict of interest in the care of people with Alzheimer's and related dementias.

We believe there is potential for conflict of interest and misuse when children of the grantor are eligible to be witnesses to the power of attorney, as the amendments to the SDA allow. As well, Bill 19 makes amendments to the Substitute Decisions Act which would allow courts to appoint service providers as both guardian of property and guardian of the person when there is no one else suitable or willing to be appointed. The prospect of, for example, the administrator of a long-term-care facility receiving compensations for services and making decisions about which services, including treatment, an incapable person receives seems to open the potential for conflict of interest or misuse.

We recommend that children of the grantor of a power of attorney for property or of a power of attorney for personal care not be eligible to be the witness to the power of attorney, and second, that the legislation provide that appointments of service providers be limited to either the guardian of property or guardian of the person where the court finds no suitable person who is willing to be appointed, and that the public guardian and trustee be appointed as the other.

A third concern under the Substitute Decisions Act is privacy. We recognize that the provisions for regulations in section 60 of the Health Care Consent Act allow rather than require health practitioners to release personal information about patients and residents. However, such personal and private information about people with Alzheimer's and other dementias is particularly sensitive. The potential harm for family members lies in, for example, theories of hereditary causes of the disease.

Although the Attorney General has made a commitment to consult the Information and Privacy Commissioner before promulgation of regulations which might compromise privacy, disclosure by persons not covered by the Freedom of Information and Protection of Privacy Act remains a concern. Particularly problematic are section 60, clauses c.2, c.3 and e.4.

We believe it would be useful to spell out in regulation guidelines which practitioners may use when judging whether information should be released and the parameters of such information, and we recommend that in considering the introduction of regulations which might compromise the privacy of people with Alzheimer disease and related dementias, the government seek comment from the Alzheimer Association of Ontario.

**Ms MacEachern:** On balance, the association finds helpful improvements which we have noted earlier proposed by the new Health Care Consent Act. We have made some recommendations in earlier parts of this brief which have to do with the act. We would now like to turn your attention to personal assistance plans and activities of daily living, an area of particular interest.

We believe that it is appropriate to formally recognize daily routines as an important component of the health

and wellbeing of an individual, and important to acknowledge that many otherwise incapable people are capable of expressing wishes about their daily routines even if they are not necessarily capable of consenting to an entire treatment and care plan. We do not believe that the way this is presented in Bill 19 entirely meets this objective.

We endorse the intent to clarify the activities of daily living as separate and distinct from treatment. As well, we support the concept as set out in part IV of the Health Care Consent Act to provide practitioner access to the hierarchy of substitutes bound by the requirements of substitute consent when a person is incapable to consent to personal assistance services. However, we do wish to make some comment.

The Health Care Consent Act introduces terminology to describe what is well understood in practice by individuals, caregivers, practitioners and legislators as activities of daily living or ADLs. We believe that the use of the common parlance would assist everyone in understanding these new provisions. Additionally, the definition of activities of daily living as described in the regulations to the existing legislation have been found to work well in practice and would appear to us to be usefully repeated in the new legislation.

#### Recommendations:

(1) That the legislation speak of "assistance with the activities of daily living" rather than of "personal assistance services."

(2) That the definition of activities of daily living be, as in the current regulations, "an activity that a person performs routinely and may include such activities as hygiene, dressing, ambulation, washing, grooming, elimination and positioning or other activities of daily living."

Consent for assistance with the activities of daily living: Very few people will be incapable of expressing consent or refusal to assistance with such basic activities of daily living as washing or toileting. Most people will be capable of making their wishes known. These wishes should be respected. In practical terms, when individuals refuse proposed assistance with ADL at a particular time, providers may approach them later when they are more amenable. We believe consent must first be sought from the person to whom the action is proposed.

Issue: People in the mid to late stages of Alzheimer disease are incapable with regard to consent for treatment. In these cases, consent may be obtained from the hierarchy of substitutes. Many people in the later stages of Alzheimer disease may very well be incapable with regard to consent to assistance with the activities of daily living. Should provision for consent for ADL not likewise be provided from the hierarchy of substitutes, who would be bound by the legislation, rather than leaving ADL decisions up to professional caregivers?

As indicated, we applaud the concept of practitioner access to substitutes bound by the act for decisions about assistance with the activities of daily living in cases where the persons themselves are incapable in that respect. We urge amendment to provide for this in all settings, not just in care facilities.

#### Recommendations:

(1) That the legislation make provision in accordance with common law that where a person is capable with regard to consent to assistance with activities of daily living, the care provider gain that consent before proceeding with assistance with an ADL.

(2) That where a person is incapable with regard to consent to assistance with an activity of daily living, and in the absence of a care plan provision, the legislation ask that the care provider seek consent from a substitute listed in the hierarchy of substitute decision-makers listed in the Health Care Consent Act who would be bound by this act.

A care plan may not cover all exigencies for assistance with activities of daily living. As well, there will be situations where consent from a substitute cannot be gained quickly. In such situations, and where assistance with an activity of daily living is taking place on a repeated basis, we urge a requirement that the substitute be informed. The substitute may then wish to consent to revisions to the care plan.

Recommendation: That the legislation require that, where a person is found to be incapable with respect to assistance with an activity of daily living, assistance may be given without consent if the caregiver has made reasonable efforts in the circumstances but has been unable to obtain a substitute consent or refusal for assistance with the ADL and that this be reported to the substitute if it is occurring on a repeated basis.

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**Mr Ellis:** Let's stop now and see whether there are questions. Members have the document in front of them.

**Mrs Boyd:** Thank you very much for your very cogent recommendations. I see that you would have gone on in section 9 to urge the government to "develop an alternative, cost-effective program of advocacy supports which utilizes the existing resources of consumer organizations." I think that's very helpful, to know that you would support that, but you need to know that we certainly think there needs to be training and coordination and so on to ensure that's there.

Equally, on the rest of your recommendations, we will look at them and take them into consideration. We know that you've presented in the past when legislation was being considered and that you've always been people who have wanted to work with the government to ensure that the rights of Alzheimer patients are respected. I think you've done it again.

**Mrs Johns:** I think in this presentation you talked about people coming in and out of being capable to make decisions and how we need to consider that very carefully. I just want to draw your attention, first of all, to section 15 in the Health Care Consent Act, which may well solve that problem. From the standpoint of Alzheimer people not in the specific health facilities we've talked to and maybe that we need to bring this act to people outside of what is traditionally a health care facility, can you just talk about how you would envision that happening or why it would happen?

**Ms MacEachern:** I think that what we would like to see is for it to expand into the community setting too. More and more people with Alzheimer disease will be



cared for in community settings, and we would like to see it expanded so that home care or VON or Red Cross, or whoever happens to be doing the service in the home, would also have consent for a care plan.

**Mr Ramsay:** I'd just like to thank you very much for your report. You've given us much here to go over. We will certainly consider your recommendations next week when we go clause by clause.

**The Chair:** Thank you for a very thoughtful report. We wish you a safe journey back to Sault Ste Marie.

## ONTARIO FRIENDS OF SCHIZOPHRENICS

**The Chair:** The next submission will be by the Ontario Friends of Schizophrenics. Welcome indeed.

**Ms Elsie Etchen:** I'm Elsie Etchen. I'm the president of the Ontario Friends of Schizophrenics. I'll be pleased to answer questions about the changes we recommend in our brief.

**Mr Bill Phillips:** I'm Bill Phillips. I'm the second vice-president of the association. I'd also be happy to answer your questions if I may.

**Ms Etchen:** In our audience today is June Beeby, who has been our executive director for years. Some of you will remember her from our previous presentations.

First, we'd like to congratulate the government on its approach to this legislation. Perhaps unlike the Alzheimer association, we didn't make a list of what we liked, because we thought we would be here all afternoon just giving you a list of likes, we're so happy about what's been happening. So we haven't done that.

It's been more than three years since we first appeared before the standing committee on administration of justice with the advocacy, consent, and substitute decisions acts; as they were then known, Bills 74, 108, 109 and 110.

**Mr Phillips:** To give you a little background, OFOS appeared before the standing committee on administration of justice twice in 1992 on the bills, and in November 1992 again we met with the government on the flaws in them. We have been a member of the ad hoc coalition. Our consistent theme has been to seek a balance in protecting rights and meeting the needs of persons with schizophrenia.

We deplore the adversarial nature of the regime fostered by that legislation. We said the complexities in it would interfere with access to treatment. OFOS thinks you have done a good job in providing a balance between protecting rights and meeting needs.

As most of you know, OFOS is a family-based organization whose relatives have schizophrenia. Schizophrenia is a biological brain disease that affects thinking, perception, mood and behaviour. Its causes are unknown, but overwhelming scientific evidence points to faulty brain chemistry or structural abnormalities in the brain. Symptoms include hallucinations, delusions and lack of motivation. Unfortunately, many people with schizophrenia have no insight into their disease and do not recognize that they are ill and need treatment.

Schizophrenia has been described by a leading American authority as "the world's worst disease, AIDS not excepted." It strikes in adolescence or early adulthood and disables most persons for the remainder of their lives.

Individuals with schizophrenia occupy more hospital beds than people with cancer, heart disease, diabetes and arthritis combined. It is the most costly of all diseases to society and government.

Schizophrenia is treated with antipsychotic medication, which in most cases reduces symptoms.

Families see early, continuing and expeditious access to treatment as absolutely essential. The bureaucratic and complex nature of the Consent to Treatment Act and the Advocacy Act have forced many health care practitioners to delay treatment. Some families find the anguish almost unbearable. Simply stated, in practice these laws do not work.

You are undoubtedly familiar with the statement that a health practitioner is required to read regarding his or her finding of incapacity and the subsequent steps of rights advice and an appeal, which result in further delays. The process under the Health Care Consent Act will reduce the hours of delay, the resulting suffering and bureaucratic requirements.

**Ms Etchen:** We thought we would not read our entire brief, since you have the opportunity to look it over. We'll just go through some of the highlights in it and you can ask us questions. We hope to leave 10 minutes at the end, as we were asked to do, for questions.

Bill 19, as you know, provides for rights advice in psychiatric facilities, which appears to restore somewhat the situation under the Mental Health Act as it existed prior to Bills 74, 109 and 110. We really don't see any need for a centralized bureaucracy to manage the provision of rights advice in psychiatric facilities, and we hope this won't be created under this new legislation. We see the rights advice that's necessary as being rather straightforward, essentially the right of appeal for an involuntary admission or a finding of incapacity.

Because of many of our unfortunate experiences with delays in treatment arising from the mandatory provision of rights advice, we are concerned about the regulation-making authority set out on page 53 of Bill 19 "regulating the timing of the treatment of a person in a psychiatric facility, if the person must be provided with information about his or her rights or if the person exercises, or indicates an intention to exercise, any of his or her rights." We think rights advice should be available in most psychiatric facilities maybe within about three or four hours. In some remote facilities you might need to extend this, but no longer than 12 hours at the very outside.

We do ask the Ministry of Health that we be consulted on the regulations before they are put in place. We don't want to see the barriers to access to treatment that have been in the past a problem for our families. We say that generally the one-size-fits-all approach to providing rights advice does not really work very well, and an imposed legislative model cannot make health care practitioners really want to provide the rights advice. We feel a legislated model not being very flexible.

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While we have the greatest respect for the work of the review board, we feel that an appeal to such a board is the end of the protection-of-rights process. So we would like to see a non-legislative model of rights advice which

encourages practitioners to cooperate with families, to cooperate with the persons who are found incapable with respect to treatment. You've all seen the long statement that practitioners have to read. Families resent this when their relative has been found incapable, so we do hope that something as rigid as that is avoided.

In our brief, we take positions on what matters most to families: improving access to treatment and providing relief from suffering for persons with schizophrenia. Most of this is taken from the brief that we wrote and most of you have seen that, since we gave all the candidates in the last election a copy of *Out of the Maze*.

Since Bill 19 has had second reading, we would say to you that we know there are some limits on the kinds of things and the kinds of changes that you can introduce. In our brief we recommend a form of outpatient commitment, which we expect is likely to be an amendment that perhaps goes beyond the authority of your committee right now.

But since most persons with schizophrenia lack insight into their disease, as Bill has said, there's need for improved access to treatment for some people. We're saying to the government, you've rethought part of the process in providing access to treatment; we now think it's perhaps time to rethink some of the other issues.

There's very considerable scientific evidence that speedy and early treatment of people with schizophrenia prevents their cases from becoming chronic, so we think that the changes in the Mental Health Act shouldn't rest with just what you have done at the present moment. Here are some other ways we think that you might improve Bill 19. As I said, we think that you've done a wonderful job, but here are some things that we think might help people with schizophrenia:

Section 22 of the Health Care Consent Act, which we outline on page 7 of our brief; the section itself is found on page 76 of the bill. I've already mentioned to Donna Bryce, your clerk, that we have unfortunately had a proof-reading error; I hope some words have been deleted so that this makes sense to you now. We apologize for the problem we may have created. We say that section 22 makes it possible for a substitute decider to consent to an incapable person's admission to a hospital or other health facility even if the incapable person objects. However, if the incapable person is 16 years of age or over and objects, a substitute decider may not consent to the incapable person's admission to a psychiatric facility.

We think that a person in a psychiatric facility should have all the procedural rights under the Mental Health Act that this act offers. But we don't see any reason for prohibiting a substitute decider from admitting an incapable person to a psychiatric facility as an informal patient over his or her objection.

Section 22 provides a higher level of procedural protection than if the person were admitted to a psychiatric facility on a form 1 under the Mental Health Act. Under a form 1, a person may be detained for 72 hours with no provision for a review. An incapable person admitted under section 22 as an informal patient has the right to apply to the review board for a review of the health practitioner's finding that they're incapable with respect to treatment. We think that using section 22 opens the door to consent to admission.

We feel that if we could have section 22 amended so that informal patients could be admitted under that section, we would have a much better way of getting persons into a psychiatric hospital than we have now, if it was less rigid than the system we have under the Mental Health Act, under form 1.

We'd like to deal with section 50 of the Substitute Decisions Act. This section provides for what are commonly called Ulysses contracts. The essence of these is that a capable person plans in advance and expresses his or her wishes about what will take place when he or she becomes incapable. The essence of our position is that we should let people decide such matters for themselves. Circumstances differ, people's needs differ, so we think the special power of attorney under section 50 of the Substitute Decisions Act should speak for itself when the person becomes incapable. Let substitute deciders, health practitioners or other persons interpret the power of attorney and decide whether or not they have authority under it.

This is not to say that amendments to section 50 are not a significant improvement over what we have now, because we agree entirely that this is so. However, families find the present law too restrictive, and to be useful, OFOS thinks families will also find the revised provisions too restrictive. In our brief, we state that the test of capacity to make a special power of attorney should be related to an understanding of the nature of the things that the grantor is giving power to his substitute to do when he becomes incapable, and we think it's critical that an assessor establish that a person understand that from the outset. Rather than they be capable of personal care, we think that the test of capacity should be that they understand the power of attorney that they're granting.

We still think the provisions for a special power of attorney should be flexible, that is, that some or none or all of the provisions or even other provisions than those that are in the present section 50 should be possible. We think that capable people should decide for themselves what rights they waive and what rights they retain and what directions they are going to give their attorney.

We think the special section that you have on revocation is absolutely essential, but we think that perhaps otherwise freedom of choice should prevail and people should be able to develop their own special powers of attorney. In this way, families will be able to work out with their relatives what they wish to happen in the event of incapacity. We think that flexibility is important, especially for persons with schizophrenia, whose capacity is episodic and who may lack insight into their disease when they are incapable.

We've included in our brief some comments on training and we hope some money will be made available to the Consent and Capacity Board to help with training and bringing people up to date on this new legislation. We commend the government for the amendments that it has made to date. We would be pleased to answer questions on our brief.

**Mrs Johns:** I grudgingly want to get into section 22, that you were talking about in the Health Care Consent Act. I think it's important to understand that there are two sides to your comment. It's important to understand



that you deal with family members or friends who need help right away, and there's another side of the populace of Ontario who worry about someone committing them to a psychiatric facility against their will.

I know that it's hard to find the two sides in this act. I guess what's happening here is that in section 22 we suggest that if persons over 16 object to going into a psychiatric hospital, the only way we can put those persons in is if they have entered into a Ulysses contract or if they have a guardian established.

With people who have friends or family who are schizophrenic and they have entered into this Ulysses contract because they have days where they're capable, days where they're incapable and they go through the process—we've had someone come in and present to us who goes through that process and says, "When I get sick, I will give you the rights through this Ulysses contract to be able to put me in an institution." What do you see is the harm in entering into a Ulysses contract with your loved one so that you are able to not have to use a substitute decision-maker and you would eliminate the problem that you're talking about in your report?

**Ms Etchen:** We think that the Ulysses contracts are the way that many families will eventually go, section 50 under the Substitute Decisions Act. We've made the list of changes that we've suggested to make it more flexible so that families can use it. Right now, there aren't very many because it's too complicated. So we think section 50 is the avenue of future planning that has to evolve.

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Under section 22, all we're saying to you is that we think that a family should, under section 22, be able to admit a person to a psychiatric facility just as an informal patient. You're not giving the authority to detain or restrain or anything like that. You're just saying to the family: "All right, if he objects, you have the authority to admit him as an informal patient." Under section 14 of the Mental Health Act, as you know, an informal patient cannot be restrained or detained. So the hurdle of getting the person into the hospital, getting them admitted over their objections—all we're saying is just remove that barrier for us and let them go in as an informal patient. If they don't want to stay there, of course they can then release themselves.

**Mrs Johns:** But in section 22, we're saying the person is objecting, so why would they stay if we bring them in as an informal patient anyway?

**Ms Etchen:** Some will. From our experience, some will. Even though they object to being admitted to the hospital, once they are admitted, some of them will stay. That's our experience with people with schizophrenia. All we're saying is, let us admit them as an informal patient under section 22.

**Mrs Johns:** I'll think about that. I'll probably have questions for you after about that. To go on to the treatment comment, what we were trying to do was to allow people who were having different kinds of treatment that were very limited treatments in the normal course of day-to-day operations not to have to go through the whole range of consent issues that came through here.

**Ms Etchen:** Right.

**Mrs Johns:** I see in one of your recommendations that you're suggesting that we allow treatment to people outside of those definitions of treatment, the narrower range, to be able to fall under the Consent to Treatment Act. Is that what you're suggesting?

**Ms Etchen:** Yes. On the activities of daily living, the persons who are in the substitute hierarchy for consent to treatment could also give consent to the activities of daily living. We think that would be advantageous. The risks are greater in giving consent to treatment than they are in giving consent to activities of daily living, so we think that the hierarchy could apply without too much difficulty. That's the essence of our argument.

**Mr Michael Brown:** Thank you for an important brief. My experience over the last eight or nine years as a constituency politician with both your group and the issues that you raise here are troubling in some respects. I don't know of any other illness that affects people in the way that schizophrenia does, and the issues around consent and seeing that the medical needs of these people are looked after in an appropriate fashion, I think you clearly tell us, is more challenging in this disease probably than in any other. That might not be a fair statement, but I think it is.

**Ms Etchen:** We think it is, yes.

**Mr Michael Brown:** This doesn't specifically have to do with the brief, because I think it's pretty clear on the issues from the way you see it, but I know that there's a mental health review going on right now and I'm wondering, are you participating in a review of the Mental Health Act and the issues surrounding that, or are you even aware of any review going on?

**Ms Etchen:** No, and we're not really aware of any review of the Mental Health Act that's presently going. Mental health reform, we participate in that. We have members on the various work groups and we have, I think, two or three representatives on the Provincial Advisory Committee on Mental Health Reform. But on the Mental Health Act itself, we're not aware of any committee or group that's reviewing that.

**Mr Michael Brown:** I was assuming that out of the mental health reform, there would be changes to the act.

**Ms Etchen:** We hope very much so. What we're saying to the government is that these amendments to the Mental Health Act only go a very limited way. What we think needs to happen is that there be a general review, and the issue of outpatient committal that we raised, we think we need that. There's a tremendous gap in the way we can have access to treatment, and that's one way that would help a lot.

**Mr Michael Brown:** I think anyone who's in this business as a constituency politician would agree that there are some real issues out there that we have to address. Thank you very much for coming forward. Keep up the good work.

**Mrs Boyd:** Thank you very much for your comments. I share Mrs Johns's concerns around your recommendations on section 22. I understand entirely why that might possibly work in a few cases, but I'm not sure that you change a law because it just might possibly work in a few cases. The case that's made by survivors of the mental health system for abuse is quite compelling.

**Ms Etchen:** What we're asking for though, we think, is less restrictive than what is the process for admission now. You can't detain a person under section 22, as we're suggesting, if they become an informal patient. Right now, if we wish to have someone admitted to a psychiatric facility and they object, we usually have to go through form 1 or go to a justice of the peace under form 2. We think this is a less restrictive avenue and perhaps fits in with the philosophy of this bill quite well.

**Mrs Boyd:** I would disagree with you quite strenuously that it agrees with the philosophy of the bill. The bill very clearly is there, and I think the best thing about this bill is that it very clearly is stating that it's important to take into account the wishes of the person most involved. So it seems to me that in fact this would fly in the face of that desire to make sure that the rights and the wishes of the person were being honoured. If in fact they are not honoured, they can be not honoured when someone is eligible for a form 1 or a form 2. That provision is already there. So it seems to me that what this does is add another level of coercion that is quite antithetical to the main purposes of the bill.

**Ms Etchen:** There would not be coercion, because under the Mental Health Act, anyone who is an informal patient can leave at any time. Under section 14, a person who is an informal patient cannot be detained.

**Mrs Boyd:** Do you think that the psychiatric facilities would in any way be willing under those circumstances to do this kind of admission? There's a great deal of cost and clerical work with each admission. Why would they want to do that if the person could leave at any point?

**Ms Etchen:** Well, they admit informal patients right now. There are perhaps more informal patients than there are involuntary patients in psychiatric—

**Mrs Boyd:** But those are people who are agreeing to go in. We're talking about against the person's will.

**Ms Etchen:** We're talking about when they object to the admission, yes.

**Mrs Boyd:** And that's what your whole issue is here.

**Ms Etchen:** Yes.

**Mrs Boyd:** There are many, in fact a large number of psychiatric patients, who feel themselves getting more and more unable to deal effectively with the stresses of their lives who will go to hospital and will admit themselves because they believe that helps. Our problem is that when someone doesn't believe it helps, when someone is resisting that kind of assistance, you're suggesting that it ought to be possible to force them into an informal admission. It seems to me that's entirely counter to all of the law that has built up over many years in terms of the protection of psychiatric patients.

**Ms Etchen:** I think perhaps we're not making our position clear. All we're saying is that the hierarchy of substitute decision-makers could admit the person if they objected. But the person doesn't have to stay in the hospital. They can be admitted, but they don't have to stay, as an informal patient. There's no coercion, there's no suggestion that the person has to be anything other than an informal patient.

1500

**Mrs Boyd:** Moving on to the issue that you raise around this extended use of the Mental Health Act for outpatient committal, I don't think there are any of us

who don't understand why that might at first blush look like a very attractive option. Certainly from the family's point of view, and we all are really aware of some of the difficulties, it may seem like an attractive option. It seems to me that it's a much bigger issue that can be dealt with. It's a very significant change to the Mental Health Act, and it seems to me it is in no way a consequent amendment to the Mental Health Act and should not be admitted under a consequent amendment under this act. There needs to be a great deal of research and study into what exactly it would mean before that would work.

**Ms Etchen:** Yes, I think we agree with you that it is a very substantial change and it's probably not possible for you to make this change. I think we acknowledge that. We want to bring to the attention of the government, though, that there's this enormous hole in the process of caring for people with schizophrenia.

**The Chair:** Ms Etchen, Mr Phillips, thank you very much for your presentation.

#### DON WEITZ

**The Chair:** Mr Don Weitz is next. Welcome.

Just initially, Mr Weitz, if I could assist you with a possible misunderstanding, because I did not know. On the front page, I should advise you that this committee is hearing anyone who requested to be heard, except for, at this point, three individuals or organizations. So I just thought you should be aware of that, because I was not at this stage. You may proceed.

**Mr Don Weitz:** Good afternoon. My name is Don Weitz. I take it you have a copy of my brief: What Advocacy? What Rights? What Justice? I will not be reading word for word, but I have some very strong words for this committee and for the Harris government in regard to advocacy and rights and justice.

I am a psychiatric survivor. I see some people have already left the room, so that's body language I carefully note. I would appreciate people's undivided attention for under 30 minutes. That would be nice because as a psychiatric survivor and an unpaid advocate for psychiatric survivors for 20 to 25 years, we rarely, if ever, have been heard or have been taken seriously inside or outside of an institution.

I wonder how many hundreds of thousands of other citizens in Ontario were denied their democratic right to be heard before this committee and the committee that heard Bill 26. I understand this is not being televised, so this is an example once more of the Harris government's denial of access to public information, particularly extremely controversial, extremely far-reaching legislation that will affect every citizen in this province.

Many years ago, I was shocked against my will, against my informed consent. For 15 months I was locked up in a psychiatric institution, one of the best-known ones in the United States, called the McLean Hospital, affiliated with Harvard Medical School and Mass General Hospital. Any of you who know about the medical psychiatric hierarchy in Boston will know that that institution is a leading experimental laboratory for the latest psychiatric treatment. In less than a month or probably a few days, I was diagnosed as schizophrenic.



The people you heard here before and the psychiatrists continually propagate the myth that there is such a disease of the brain called schizophrenia. I have carefully read and looked at literature on schizophrenia for many, many years and there is not one shred of credible scientific, genetic, biological, medical evidence to justify calling so-called schizophrenia a disease of the brain or anything else.

I was diagnosed schizophrenic simply because I refused to shut up about my anger and because of my dissident behaviour, which was quickly pathologized as mentally ill or schizophrenic. Thousands of people in Ontario today, as we speak, are also being unjustly, fraudulently labelled or diagnosed schizophrenic simply because their families or others can't or choose not to understand them, to understand their communications, which may be very poetic and metaphysical as well as troubling.

It is a complete fraud, this whole thing of psychiatric diagnosis, particularly with schizophrenia and, by the way, the label never leaves. I mean it's like glue, once you're labelled schizophrenic, you're always schizophrenic. It doesn't matter if you go on to become a chief executive officer or a politician in Ontario. Once doctors have the stigma labelled on your chart, it stays there. Forty-five years after I got out of McLean Hospital, I know damned well it's still on my chart. This follows me wherever I go. If anybody wants to look up my records or has access to them, they can get it, at least in the States.

I was tortured with insulin shock. Those of you who know what insulin is will know that it is extremely powerful and the only legitimate use is for the treatment of diabetes, thanks to Dr Frederick Banting, Best and others. By the way, Banting never spoke out against the use of insulin in psychiatry despite the fact that he was aware it was being used. It would have been nice for him to speak out, which would have saved maybe a few hundred lives here and in the United States.

I was lucky. I only went into a coma once. My doctor never warned me about a coma, never warned me about the tremors or convulsions or profuse sweating that always occur, just as doctors and psychiatrists today conspicuously and routinely fail to inform their patients about serious risks, including brain damage from electroshock, which is going on as we speak in Ontario, or aversive shock, which Sharon Danley referred to earlier today in her presentation for Survivors of Medical Abuse.

This is a disgrace. This is a massive human rights violation, a crime against humanity that electroshock, 130 to 150 volts plus to the brain, and that's true, which always causes an epileptic seizure and coma or unconsciousness, is still allowed as a legitimate medical treatment. It should have been outlawed, it should have been proposed, it should have been banned in the Consent to Treatment Act or rather in the Health Care Consent Act just as psychosurgery is banned for involuntary patients.

1510

If psychosurgery is so bad for involuntary patients and cannot legally be prescribed, why the hell isn't it banned for voluntary patients? Is there something different in the

brains of people labelled voluntary that enables them to be immune to the brain mutilation which always occurs with psychosurgery? I don't know. Mike Harris talks about common sense. There doesn't seem to be much common sense in this government. There seems to be a lot of nonsense, a lot of insane nonsense when it comes to protecting people's lives and bodies.

During the last six years—I won't get into my biographical stuff right now except to say that I have a radio program called Shrinkrap, the only anti-psychiatry program in Canada to my knowledge, which finally exposes some extremely serious psychiatric abuses and tries to help. I do whatever I can to help empower psychiatric survivors who have been put down, who have been seriously abused by the system.

I now get to rights advisers. Under your government's draft Health Care Consent Act, rights advisers are totally wiped out, so no one actually is going to find out what their rights are. Oh, that's terrific. Except if you're a psychiatric patient, then for some reason the rights advisers only let you know that you can appeal a judgement of incompetence or incapacity, a very damning, all-encompassing, stigmatizing term, I may add, because we are all capable and competent in some aspects.

Nevertheless if you're in Toronto General or St Mike's and you don't know whether you can say no to any treatment or operation and Aunt Betsy has a right to sign the form for you while you're about to go under electroshock, that's too bad. That's just too bad. You're up shit creek. That's it. Too bad. You get no free advice about your rights and about your right to speak out and save your body and mind or health. Too bad. That's what this government is saying to hundreds of thousands of citizens. It's unconscionable, it shouldn't be allowed. It should be criminal. It is criminal.

By the way, it seems that advisers can be nominated or chosen by the director of any medical institution so that anybody who works in that institution can be an adviser. That's conflict of interest. I guess some of you should know a lot about conflict of interest because you yourselves may have been charged or been accused of conflict of interest here in the Ontario government of before. It looks like you've enshrined conflict of interest for some rights advisers in the province of Ontario. Congratulations. How about independent rights advisers or is that too radical?

In the treatment section here in the Health Care Consent Act, it says under (g), "a treatment that in the circumstances poses little or no risk of harm to the person." That's not considered a treatment. Psychiatric drugs like the neuroleptics and anti-depressants, electroshock and/or aversive shock—that's the use of the cattle-prod variety, which are known to be high-risk, health-threatening and behaviour modification procedures—can easily be interpreted as having "little or no risk of harm" especially by the psychiatrists.

"Oh, we're just going to give you a little jolt in the brain, Aunt Betsy, and pretty soon your depression will be lifted and you'll have no memory loss." That's bullshit. There is always memory loss. It's not a question if there's damage as Dr Peter Breggin, the most world-renowned critic against electroshock and psychiatric



drugs, is saying. The question is, does the patient recover? That's the question. Doctors cannot really give or very few give an honest answer in the medical psychiatric establishment in Canada. Does the patient recover?

Best interests—oh, I should also add under treatment, most psychiatric patients, as you know and you will hear from other people coming before you today and it should be common knowledge by now, are not being fully informed about any psychiatric treatment, particularly the drugs. I wish I had a dollar, I'd be very rich, for every person who called me up at night or something: "Don, I wish I had known about tardive dyskinesia. Tell me about it." Tardive dyskinesia is one of the most serious, permanent neurological disorders resulting from any one of the 20 neuroleptic drugs approved by the drug formulary.

Do you think the doctors are going to inform you about that? Four years ago, the Clarke Institute finally decided to have a three-line explanatory note about tardive dyskinesia 20 years after the fact. Thanks a lot. In the meantime, a lot of my brothers and sisters were permanently brain-damaged by the miracle neuroleptic drugs. This happens to 30% to 40% of the people who are on any one of 20 neuroleptics four or five years or longer.

You won't get that information from the Clarke or Queen Street where they hand these brain-damaging drugs out like candy. Is there any protection here? Oh, yes. It says, "You're supposed to tell the patient about informed consent." It looks good on paper. "You're supposed to tell them about possible risks." Yes, you're supposed to, but let's get real. The reality is that no one is monitoring the doctors. No one is looking after them when they lie to your face and your family to warn you about the risks so you can make an informed decision.

Do the doctors tell you about safe community alternatives, non-medical alternatives like self-help or support groups? No. No, not on your life. Why? Because that would be threatening. It takes too much power away from them because they think they have all the answers, which obviously they don't.

Best interests. Oh, that's a nice-sounding term. What does it mean and who decides? Under the Health Care Consent Act, consider these subsections regarding factors. The substitute decision-maker, the person who's supposed to make these fateful health care decisions for you, must consider when deciding what the person's best interests are.

It's under subclauses 19(2)(c)(i), (ii) and (iii). Two of the very controversial points that the decision-maker has to take into account are: Does the treatment "(ii) prevent the incapable person's condition or wellbeing from deteriorating, or (iii) reduce the extent to which, or the rate at which, the incapable person's condition or wellbeing is likely to deteriorate"?

Well, I've got news. No one has a crystal ball to tell you, in psychiatry particularly, whether treatment's going to work or not. It's usually guesswork. And guess what? A layperson has a better chance of predicting so-called dangerous behaviour in a patient than the psychiatrist. It's like flipping coins in the courtroom. They can't predict.

There's a lot of documentation showing that psychiatrists cannot accurately and reliably predict behaviour,

particularly dangerous or problematic behaviour, yet they are given the power to do so. This is a totally unrealistic bit of nonsense to assume that someone's going to say, "Well, it's likely to" or "It's not likely to." Hey, don't call it medicine. Call it a sideshow or quackery. It's quackery; it's not science that we're talking about here. You're enshrining quackery in your Health Care Consent Act.

#### 1520

Aversive shock: Take a look at The 5th Estate's first-rate document called *Short of Miracle* aired I believe it was on January 2. Go ahead. If you think aversive shock is so good, go ahead and take a look at whatever his name is giving shocks to brain-injured kids in Chedoke McMaster Hospitals. This is not 1850; this is the 1990s. The kids, already brain-damaged, are being further damaged by shocks to different parts of their body. You know, the kids who wear a helmet and everything, and adults. This is allowed in compassionate, understanding Ontario. That's terrific, something to be proud of, that we're damaging brain-damaged kids. Take a look at the documentary from The 5th Estate, *Short of Miracle*; I mention it in my brief.

You think that's bad; of course, it's worse. The substitute decision-maker can decide whether their child can be subjected to this torture masquerading as treatment or rehab, at one of the government-funded institutions, a big, big-time institution, Chedoke McMaster in Hamilton. It should be banned. This doctor should have been charged with criminal assault and everybody that helped him. Electroshock—I mentioned it—still allowed. It's unfortunate. There are only about 1,700, 1,800 Ontarians, people of Ontario who are being shocked every year, 130 to 150 volts, going through epileptic seizures because they happen to be too grief-stricken or too depressed, and especially if they're an old woman. Do you know that 40% of the people who get shock in Ontario are 60 years and over? Where do I get that statistic? From your own Ministry of Health. Wake up. If you're an old person, especially if you're a woman, because twice as many women as men get shocked so there's a sexist angle here too, but there's an agist one too. This is a new form of elder abuse.

What are you doing about it? Nothing. Do you want a copy of my statistics? No, you go and ask the Minister of Health, Jim Wilson, who apparently turns a blind eye and so forth; I mean, apparently he is on some other planet, to tell you the truth. In fact, I don't know where Wilson is, to tell the truth, except he and Harris seem to agree on fascist initiatives.

Okay, I've got to leave some time for questions, but I just want to end here that I want you to withdraw—I'm making a demand on you as a citizen. I'm asking you—that's all I can do—to withdraw this bill, which has got so many flaws in it, which apparently was drafted without adequate consultation with citizen groups, and start over again. Start being guided by the Charter of Rights and Freedoms, the top law in Canada, which Ms Danley referred to, because I'll tell you, there's going to be a bunch of charter challenges in the court. If you're prepared to fight that's fine, but you're going to be challenged. There are going to be charter challenges



under section 12, section 7 and section 15. So I just want you to be prepared.

That's all I've got to say. Thank you. Questions?

**Mr Ramsay:** Don, thank you very much for your presentation. In fact, I see there's much more there than you addressed today. I'll complete that because I see you've got a chapter on emergency treatment, which we're certainly concerned about, that I'll go through. You go on about notice of continuance. So I'll finish going through it. Would you have a suggestion, since the Advocacy Act is being repealed by this government and because there are financial restraints, on maybe what type of a replacement could be put in place for advocacy in Ontario?

**Mr Weitz:** Sure, I have some ideas. Given the fact this government has killed government-supported, sanctioned advocacy, so there's no possibility of investigating systemic advocacy, I think the best that can be done is to support those groups that already have some kind of a track record in being advocates, and there are some probably attached to legal clinics. Of course, it would be great if the money were made available; I don't know how much, but as far as I'm concerned there really can't be enough to support grass-roots, citizen-controlled peer advocacy. I myself am thinking of getting much more actively involved in this whole area of community-based advocacy. Anyway, that's all I've got to say about that. It's too bad it's being killed.

**Mrs Boyd:** Thank you very much, Mr Weitz, for your presentation. I think it's really helpful for us to be reminded of how many treatments have been considered low-risk and very efficacious by medical and psychiatric doctors in the past that we now know in fact to be quite destructive. The insulin coma issue is one, but there are many, aren't there, that have been used over the years?

**Mr Weitz:** Oh, yes.

**Mrs Boyd:** Their advocates come and tell governments how important they are and in fact get research dollars for doing them and fight to make sure that they can continue to provide those treatments in spite of the damage that can be seen to be caused.

**Mr Weitz:** I'll tell you something: Fortunately, insulin shock stopped in the mid-1960s or late 1960s in Ontario and the United States. Of course, the real reason why it stopped was because there were deaths and quite a few serious medical complications; the real story about insulin shock hasn't been told yet, as far as I'm concerned. But as we speak, Ms Boyd, the Clarke Institute is getting money, probably close to \$1 million, to do continued research and monitoring of electroshock. That's the shock shop of Toronto, okay? The Clarke. As far as I know, that's the shock shop in Ontario. They have a separate unit. People are getting brain-damaged as we speak, including permanent loss; they don't remember. I mean, this is allowed. Who's to speak for them? Now there are no advocates in the Clarke; there never have been. There will be no advocates in any health facility to help people say no and to get redress or appeal.

This violates the charter, as you know, because there'll be no appeal mechanism. You're not being informed. This is a crime against humanity. I'll say it again: Electroshock is a crime against humanity, just as insulin shock was, just as the drugging of neuroleptics is. No one

is speaking out. No nurse that I know of has spoken out against it. Certainly no medical doctor has. They're a bunch of wimps in Canada. There are about about eight who have spoken out in the United States. We have none in Canada who are concerned about the brain-damaging effects of this treatment, the drugs and shock.

**Mrs Boyd:** Dr Thomas Szasz calls it the second sin.

**Mr Weitz:** Yes. I wish we had someone like Szasz here.

**Mr Parker:** I just want to say that I'm very grateful to you for coming in this afternoon. I listened carefully to every word that you had to say. I think we will all find your comments and your recommendations very instructive. Thank you, sir.

1530

## ONTARIO RESIDENTIAL CARE ASSOCIATION

**The Chair:** Next is the Ontario Residential Care Association, Mr Rick Winchell. Welcome.

**Mr Rick Winchell:** Last week you heard from a regional representative of the Ontario Residential Care Association when you were up in Ottawa. I'm the association's executive director and I appear today on behalf of our members across the province.

As you're aware, ours is a voluntary organization of retirement and residential care owners and operators. The association is constantly evolving. In fact, over the past three years our representation of care homes has virtually doubled to more than 220 facilities. We specialize in providing personal care and assistance with activities of daily living for about 15,000 residents. To deliver the care our member facilities employ about 10,000 people.

Across Ontario there are approximately 23,000 residential care beds. The average age of residents who occupy those beds is about 84 years old, an increase of five years over the past decade. In some jurisdictions in Ontario residential care facilities also are home to a younger population of disabled and post-psychiatric residents.

Residential care plays an important role in the long-term-care continuum. We fill the increasing gap between home care and the care and support services delivered by nursing homes and homes for the aged. As our population continues to age and the demand for a limited number of long-term-care beds increases, we fully anticipate the contribution of our sector will continue to grow proportionately.

With the exception of the Residents' Rights Act, 1994, which really involves what I'd call inappropriate application of the Rent Control Act and Landlord and Tenant Act, residential care facilities are not provincially regulated. There are a number of municipal bylaws which, for the most part, are inconsistent and questionably enforced.

What sets our member facilities apart from non-member residential care providers is our comprehensive standards evaluation program. No facility is accepted for membership without passing a thorough, independent operations review. Even then, we have different levels of certification and re-inspect any care home which undergoes a change in ownership or demonstrates gross non-compliance with our standards.

My Ottawa colleague last week pointed out that we participated in committee hearings involving these acts in



the early stages of the previous government's mandate. Like many health care provider groups across the province, we expressed concerns around the Advocacy Act.

We strongly believe that by its own definition a successful advocacy initiative should result in the need for few, if any, provincially designed advocates, since the spirit of the concept involved moving towards self-advocacy. In fact, the residential care environment has long promoted the rights of residents to make their own personal decisions. It is our belief that delivering quality care can only occur when done in a setting that encourages individual dignity and autonomy.

We urged the previous government to test its Advocacy Act on a pilot basis, since we were concerned with the complexities of the proposed system. We were concerned that the system carried the potential to promote confrontation between caregivers and advocates. We have qualified registered and support staff who contribute to a caring environment. Most importantly, our staff is committed to delivering care which is based on the stated health and lifestyle goals of our residents.

We applaud the government's move to repeal the Advocacy Act. Given the nature of our client base, we further endorse changes involving the Substitute Decisions Act and the Consent to Treatment Act intended to reduce red tape and strengthen resident support through timely care delivery.

We do, however, suggest that there may be an expanded role for the public guardian and trustee to intervene on behalf of our residents when family members or designates demonstrate ongoing negligence. The PGT has historically been reluctant to investigate matters on behalf of residents.

As it stands, providers have limited options in dealing with negligence. By way of example, I recently received a call from a facility administrator who wanted advice regarding an extraordinary payment problem. Despite countless attempts to collect accumulating arrears, the resident's daughter built up a five-month debt.

The administrator enquired about eviction procedures, something which I can tell you that in my 10 years with this association I've not experienced. She had no intention of actually evicting the resident. On the contrary, she was actually considering taking the resident to her own home as a stopgap measure while she works with the area placement coordination services for an alternative solution.

The only leverage that this administrator has to settle the account involves a court-ordered eviction under rent control laws, which is clearly not in the resident's best interests. Furthermore, she strongly suspects that financial abuse could be the source of the problem. A court order is currently being sought in the hopes that the daughter will finally respond; she's been ducking every request to this point. Meanwhile, the resident remains in the facility and the administrator continues her chase for the daughter. Clearly, in cases such as this, the involvement of the PGT would be a much-welcomed assistance.

We have other suggestions: It's our belief that rights advice, as it currently is detailed in the act, is a system that is both restrictive and one-dimensional. We support the government's position to delete the formalized rights

advice from the Consent to Treatment Act. People familiar with residential care settings will know that, as a standard of practice, registered staff will provide rights advice and non-registered staff, such as administrators, are committed and willing to provide residents with rights advice when needed. We prefer a flexible approach, as opposed to the cumbersome system that exists currently.

We also suggest that there may be merit in applying the hierarchy of consent to include residents of residential care and retirement homes. It seems both impractical and costly to force family members to hire a lawyer to arrange for a power of attorney in cases where residents are deemed incapable of making a decision.

We also wonder if there may be further merit in expanding the personal assistance plans to include services beyond just long-term-care facilities, because as you all know, personal care planning is equally important in the delivery of all long-term-care services, including residential care.

We think, however, that the capacity threshold as proposed in Bill 19 may in fact be too high. The proposed concept could be counterproductive if the approval for a care plan by a substitute decision-maker actually overrides the ability of residents to make routine daily decisions involving their personal care. Encouraging residents to participate in routine decision-making is in fact a vital component of any meaningful personal care program.

My Ottawa colleague also addressed the revolving door syndrome that we as residential care operators experience with our post-psychiatric population. It's our belief that inclusion of the Ulysses contract, coordinated perhaps through social services, could achieve a couple of important goals.

First, when a general welfare assistance resident's condition deteriorates in an independent community setting, appropriate care decisions could be made on behalf of that resident based on his or her wishes, which may have been expressed at a healthier time.

Secondly, care intervention could occur early enough to avoid costly and unnecessary readmission to a psychiatric facility. So through the Ulysses contract, a person showing signs of deterioration could be readmitted to the familiar and supportive residential care surroundings of his or her choice.

Overall, we are pleased with the proposals as they are laid out under Bill 19. It's our hope that our comments today have been productive and we thank you very much for the opportunity to appear before you.

1540

**Mr Marchese:** Mr Winchell, thank you for your presentation. I'm tired, so I'm more likely to be more gentle with those with whom I disagree. The way I see it, I like defending those who are likely to be abused by a system. I like the idea that we have systems in place that make sure that we deal with negligence, exploitation and abuse. It worries me and it concerns me when a number of caregivers and individuals who have suffered abuse come in front of this committee saying: "We need the Advocacy Act. We need the commission. We need right of entry. We need rights advice." So I take my advice from them, because they're the ones who are closer to the



problems. I understand what doctors say, I even understand what a few of the lawyers say about how some of these things affect them, but on the whole I am guided by the people in the field and those volunteers and those caregivers and many others who are close to people who suffer negligence and/or abuse.

Being guided by that, it concerns me when people like yourself come here and say: "We're happy that the Advocacy Act has been repealed. We applaud the government's move to repeal it." That concerns me. You then say as well, on a separate point, "We suggest that there may be an expanded role for the public guardian and trustee to intervene, on behalf of residents, when family members or designates demonstrate ongoing negligence." Interesting suggestion, but like the Human Rights Commission, which is there to support people's rights, it's driven by complaints. If a complaint doesn't get there, it's as if the complaint doesn't exist. So we all assume that there's no problem.

We need a system in place that is able to get to those abuses, a system that advocates generally for all those people. We need a system that allows people to be able to enter premises where it is suspected that there might be a problem, so it can be dealt with. Someone needs that authority; otherwise volunteers and other agencies that deal with these problems can't get to the problem. As much as that proposal seems useful to you, for me it doesn't do the job of getting to the real abuses. Do you have any suggestions or comments to what I said?

**Mr Winchell:** What if I said no?

**Mr Marchese:** I'm sure that it would be simple enough.

**Mr Winchell:** I'll start with the last point first. The fact is, I can't speak for the entire health care system. I'm speaking specifically about the residential care sector. I personally, having spent the last 10 or more years working in this particular sector, believe very much in the concept of professional, caring staff who have enough common sense and antennae, if you will, to spot problems before—I think there's not enough credit given to the people who in fact are working with the residents day in, day out. That's the way I would respond to your first question.

The second point: I'll take you back to 1973-74. I was this province's very first patient ombudsman, at the Lakeshore Psychiatric Hospital. It was a test, a pilot, and I can tell you from very personal experience that done in a non-adversarial situation it in fact can be a part of the whole therapeutic milieu. I'll go as far as to say that in many cases the staff initiated the calls to my office because they saw the merit in assisting the psych patient to pursue and investigate situations.

But I will also say that when you take that system, and I don't know how to articulate this any better than to say, when you shift it into an adversarial environment, you've defeated the whole purpose of trying to assist both staff and residents. I can also tell you that after a while, when you get into—and believe me, I defer to the experts today, but I have heard that since that pilot has expanded into the psych system, it has become extremely adversarial. I guess my problem is that when we talk about advocacy, I believe that educating people to understand

their rights is important. I do not believe that having a bunch of police going around standing over the shoulders of care providers is the solution. That's the way I see and interpret the current—

**Mr Marchese:** I understand. There's no doubt that many of the people who provide care to vulnerable people, people with disabilities and the elderly, are doing their best. There's no doubt about that. I'm concerned about where there are abuses and how we deal with that. Your suggestion is that what we have in place is controversial or is—

**Mr Winchell:** Adversarial, and ineffective.

**Mr Marchese:** In my view, if you don't have that system in place that we are recommending, then everything else in terms of how we deal with abuse is hit and miss. We don't know how to get to those problems. If we're lucky enough, we'll find a problem and we'll be able to deal with it, because there's no systemic way of getting to the abuse. I'm not quite sure what you're talking about when you say "some non-adversarial system," but I'm not aware what you're proposing that gets to the matter of abuse.

**Mr Winchell:** The fact is that it doesn't need to be adversarial. When you start to appoint quasi-judicial people with legal backgrounds, I guarantee you, you are inviting an adversarial system that does no one any good. I can only speak from my own experience. I worked four years as a patient ombudsman. I did not have problems with staff, I did not have problems collecting information and I sure didn't have problems getting the support of legal aid or any other source that I needed to resolve a patient's problem. I'm sorry, I've lived in a situation where it's not adversarial; I do not want to move to a situation where it is. And I know that the one that's not adversarial can be effective. That's my own personal experience.

**Mr Parker:** Thank you very much for coming here this afternoon and for sharing your thoughts and views with us. It's nice to hear that you see much in the proposed bill to support. We're grateful for that support.

We've got some time here. I wonder if you could just help me out with one element in your paper that I didn't quite grasp. It's towards the bottom of page 3, the second-last paragraph towards the bottom, where you refer to section 18. Your suggestion is that we apply "the hierarchy of consent (section 18) to include residents of residential care and retirement homes." Can you just flesh out that for me?

**Mr Winchell:** Yes, sure. Under the hierarchy of consent right now, my understanding—correct me if I'm wrong, any experts—is that it applies only to those family members involved with residents in long-term-care facilities, those being nursing homes and homes for the aged, so that when the person becomes incapable of making decisions, there is a list, starting with power of attorney and working its way down. What we're suggesting is that you may want to consider applying that hierarchy of consent to include family members of those in residential care facilities. Did I explain that?

**Mr Parker:** I think you did, and I think that you have imposed a limitation on this—

**Mr Winchell:** Okay, maybe I have. I stand corrected if I have. The way I understand it right now, it's limited



to the long-term-care facilities, and residential care, as it's defined today, unfortunately does not fall under long-term care. We are a very big part of the long-term-care continuum, but we are not defined or recognized by government as long-term-care providers.

**Mr Klees:** Mr Parker, could we just ask staff to clarify that point for us?

**Ms Trudy Spinks:** I don't normally comment on the health care consent side, but it's my understanding that the way part IV of the Health Care Consent Act is drafted now, it applies to long-term-care facilities—nursing homes, homes for the aged and homes under the Charitable Institutions Act—and that there is regulation-making authority to add other facilities there, but that at the moment it only applies to regulated long-term care.

**Mr Winchell:** So we in fact are not covered by that section; the hierarchy of consent does not apply to any members of families who have family members in retirement homes.

**Mr Parker:** Okay, thanks. The instruction we're getting from staff there, if we've all understood the provision correctly, is that that could be addressed by way of regulation. Thank you for your guidance on that point.

**Mr Klees:** I'd like to pursue a matter with you that has been discussed by others here, and that is that we're all aware that there are abuses in the system. I've personally had opportunity to be in homes for the aged where, quite frankly, I didn't like what I saw. What I would like from you, as someone who has a vested interest in ensuring that that industry is providing quality care, is, what can be done to ensure that the standards are maintained to the standards that you, I know, insist on probably for the facilities that you're directly involved in?

**Mr Winchell:** I could give you a very long-winded response to that. You're hitting a hot button for me that doesn't necessarily involve just Bill 19. We have for a long time worn a path to Queen's Park attempting to establish province-wide standards specific to residential care facilities. The previous government's response to that was to apply apartment laws to care homes, and if you've ever been in a care home, you'll understand that needs change on a daily basis, so to require 24 hours' notice before you go into someone's room is absurd. The application without any modifications whatsoever of the Landlord and Tenant Act and Rent Control Act is totally inappropriate.

We would love to see this government adopt standards specific to residential care, and I don't think it's going to go away. This is one part of the long-term-care sector which is growing in leaps and bounds, simply because there's a cap on long-term-care beds. We would like to see province-wide standards enforced municipally. We would like to see the municipalities charge on a recovery basis. Go into the homes, license them. If they aren't complying, close them down. We believe that not enough is being done to police some of the bad apples in the residential care sector, and believe me, there are some. We know they're out there.

1550

**Mr Klees:** What we're really talking about is getting at the root problem. Rather than perhaps being preoc-

cupied with advocacy at the top, let's get to the root problems, solve those problems, and you need less pure advocates to deal with that issue.

**Mr Winchell:** Absolutely. You're absolutely correct. The previous government refused to listen to any alternative other than applying apartment laws in a care home, when in fact what we were arguing was that if we had province-wide standards municipally enforced under a cost-recovery basis, first, we don't need the advocates to the extent they believe, and second, we can actually enforce the licensing process. Right now there's no enforcement whatsoever going on out there. Deal with that and then let's talk about advocacy. If there's still a need, I'll happily come back here.

**Mr Michael Brown:** I appreciate your presentation. I had the dubious honour of chairing the committee that did the clause-by-clause evaluation of Bill 121. I agree with you that it is certainly an inappropriate use of two acts that had virtually nothing to do with what you're about.

Anyway, I was wondering, along the same line as Mr Klees, what's the answer here for your industry in particular? We all know there is a need for advocacy at some point, probably done in ways quite different from how the former government went about it. In some situations, and you point one out, we could have the public guardian and trustee move in. It is disturbing to me, knowing that, but it would be more disturbing if it has to do with personal care or health care than the money example.

**Mr Winchell:** I refer to the public guardian as a last resort. More important, I can guarantee that with the public guardian as a last resort, it provides our administrators with a lot more leverage than they currently have to negotiate with family members who may not be keeping on top of things.

In terms of care, I should also tell you that for the past several years our association has had a very comprehensive consumer information program. Anybody who wants to know anything about residential care can call our 1-800 number. By the way, we're non-apologetic about the fact that we promote our members and the standards they stand by, and we are again non-apologetic about advising people, if they are in the market for a retirement home, to make sure it is an approved member of our association.

Having said that, we field on average 60 consumer calls a week. The majority of those calls are inquiries. Several are complaints, and of those that are complaints, I'd say the majority are involving non-member facilities. I investigate every one of them. Where I run into a problem, though, is that when I'm dealing with a non-member, they can basically tell me to fly a kite. If we go back to what Mr Klees was saying, if there were enforceable standards for retirement homes and residential care facilities, it would make my job a whole lot easier to clean up some of these problems red-flagged by consumers.

**Mr Michael Brown:** Does your organization have any idea of how many residential care facilities may not belong to your organization?

**Mr Winchell:** Yes. I can tell you that we represent about 60% of the 23,000 in Ontario. There are those who



don't join because it's a voluntary, discretionary dollar they'd need to part with, and then there are those who would never qualify because of our standards.

**Mr Michael Brown:** Does your organization provide for any kind of inspection of its member facilities on an ongoing basis?

**Mr Winchell:** Yes, sir, a very comprehensive standards evaluation program that's done on an independent review basis. It depends on the level of certification. If a person gets a two- or three-year, we may not be back for the two or three years later. However, in the meantime, through our consumer program, if I start to see a trend of inordinate numbers of complaints of a member facility, obviously we act upon it.

The other thing is that we have a fairly comprehensive monthly media clippings service, so that even if we don't hear about it or read about it in the Toronto stuff, we get everything from Wawa to Cornwall and we find out a whole lot about stuff going on in our business that routinely would be missed. We're constantly, constantly keeping an ear to the ground.

I could bore you with the details of what we're trying to do to inform the consumers about how to make an informed decision when it comes to residential care. Believe me, it's something we're committed to, and if we had an open chequebook we would have probably achieved our goal by now. But it's an ongoing evolution. We distribute, for example, a very comprehensive consumer directory that details how to evaluate a residential care home, how to make sure that what you're choosing can meet your needs, and if you have any questions, call our 800 number. I could go on and on, but I sense that the Chair is getting—I just want to say that the whole aspect of educating the consumer is in my definition part of the whole advocacy concept and we're very committed to that.

**The Chair:** Thank you, Mr Winchell, for taking the trouble to attend today. It's been most valuable.

## CONSENT AND CAPACITY REVIEW BOARD

**The Chair:** Our next submission is from the Consent and Capacity Review Board. We welcome Mr Michael Bay, chair. No doubt the committee has been looking forward with great expectation to your attendance here today, Mr Bay.

**Mr Michael Bay:** Thank you for the greeting, Mr Chair. I have to admit that I take some satisfaction in seeing a group of people having to share, at least for some weeks or months, in the agonizing task that my board members and me have year after year after year: balancing, on one hand, individuals' civil rights, their rights to autonomy, self-determination, "Leave me alone," with their medical care rights that we owe vulnerable people as a society. It's a rather never-ending battle, balancing those two kinds of rights. It's with pleasure that I watch you folks engaging in the same thing. I don't know whether it's a shared sense of mission or a shared sense of pain. I'm not quite sure.

I'm not going to read the brief we've circulated—I had a professor who taught me not to do that—but I have some other remarks for you.

As I note in our brief, the history of the board goes back a long way. Legal supervision of involuntary admission to psychiatric facilities actually began in the common-law world in England in 1817 and exists now in every Western democracy. Our board was created in 1968 under the Mental Health Act. The Consent to Treatment Act, when it came into effect last year, theoretically abolished the old psychiatric review board and created a new one, but that change was really only on paper. In fact, we have members who've served on the board since 1980. I moved from the ministry legal branch to the board in the late 1980s myself and was moved up to the position of chair last year.

Eighty per cent of what we do at the board is involuntary committal under the Mental Health Act. So while we're involved very much in the issue of substitute decision-making and capacity, the primary mandate of the board is really one of public safety.

Unlike most government agencies, the board meets in hospitals, nursing homes and living rooms to dispense its justice. I tell people, kind of laughingly, that we're some sort of cross between the Ontario Court (General Division) and Pizza Pizza. We think of ourselves as a service provider, and we're proud of our level of customer service and our response time.

The board is organized in a way that's quite unique for government. Our day-to-day work outside of head office is managed in nine regions around the province. Each region is headed by a vice-chair who's a lawyer in private practice, who works for the board on a part-time, as-needed basis and does the work out of his or her own private office and provides his or her own staff to us on an as-needed basis. We, I think appropriately, have been referred to as a virtual agency. You can get us by phone or fax and we'll come out to you, but if you look for our offices in the regions, they don't really exist, and they don't cost the government anything.

## 1600

Under Bill 19, our areas of jurisdiction rise from 12 to 22. Our costs could increase substantially if these changes are not accompanied by appropriate streamlining, and we need your help for that. We hope that amendments to the bill will extend from seven to 14 days the time period we're allowed to utilize, in some of the cases that come before us, in scheduling our hearings. This would permit more time to allow settlement and allow more flexible scheduling to lower costs. Again, this proposal isn't in the bill that's tabled before you.

We are gratified that the government has included in the bill a number of our proposals for streamlining. I have to say that we found the Ministry of Health incredibly open during the drafting process. Without these changes, we'll find it very hard to do our job within a reasonable budget. As you all know, in every area of government, if we've been assigned new tasks we have to find the money somewhere. I doubt very much whether the minister is going to send a cheque down to my office by courier. I could be wrong, but I suspect I'm not going to see any new funds. I need your help in functioning with what we've got now.

The first of the proposals we've tabled, right up front that we asked the minister and the minister accepted it,



was the reduction in panel size. That isn't in all cases. We've asked to be allowed to reduce panel size, at our discretion, in some types of cases. It could only apply in about 27% of our cases, because it wouldn't apply in involuntary committal or things related to that. Our intention is to apply this provision very cautiously, and I give you that undertaking. We expect that no more than 5% to 10% of our total hearings would be with a single member, at least at the outset. This could go maybe to 15% to 20%; it couldn't go over the 26%, and I doubt it would go that high. That means that depending on how many hearings go down to a single member, conservatively, our savings annually would be between \$40,000 and \$160,000. In the government scheme of things, that's not a lot of money; in managing my board, that's a whole lot of money.

We've been very cautious in our recommendations, and I think they've been incorporated into the bill—in fact, the drafters were even more cautious—in defining who could sit as a single member. A single-member board could only be chaired by an individual who's qualified for appointment to the bench, that is, a lawyer with 10 years at the bar. In addition to that, though, a member chairing a single-member hearing would have to have a minimum of two years' experience on the board and have expertise in capacity adjudication, thus preserving, we believe, the requirement for expertise in capacity. They would also have to meet any other criteria that I, as chair, or my successor over time would set for them. It's going to be a very small and elite list of people. It's not meant to be any lawyer appointed to the board. The result, we believe, would be the availability of a flexible and inexpensive way to respond to some applications to the board.

I should add that we're not doing it just for financing. I am, quite frankly—and I say this as someone who believes in this work and who quite loves it and has been doing it now for seven years—terrified of going into nursing homes and long-term-care facilities and doing hearings with a three-member panel and a court reporter, and the family on one side and the elderly, frail, very frightened, confused person on the other side, and I have to run something right out of Clarence Darrow. I don't want to do it. What we're desperate to do is to let the air out of the tires. We're moving very quickly to a dispute resolution model in those cases. We find very often that case conferencing hasn't been done etc, and if we can go and do those sorts of things we can make the problem go away to everybody's satisfaction.

But even when we have to have hearings, we're desperate to do something to let the air out of the tires, as I've said, and we think a single member will assist us in doing that, in allowing the member to be a little more flexible, a little less formal, while preserving rights and being sure that everybody is properly heard and dealt with.

To focus that a little more—and I don't say this flippantly at all—my concern is that we're going to end up with something that looks like estate battles, except that the body's still warm. I really don't want to do them and I'm quite frightened by them, so that's another reason we're very anxious to move to the single-member model where appropriate.

Another request we've made is the elimination of the automatic requirement for written reasons. Written reasons would continue to be available on request or when the board felt they were necessary. So we would continue to have reasons available while avoiding the expense of paying to have reasons issued in cases where there's no need for them. Don't forget, all the people on my board, except for me, are fee-for-service, so if you want reasons in every case they have to be paid for, and we'd prefer to use the money somewhere else.

We're not saying that reasons won't be asked for or be necessary in 80% or 90% of the cases. We're trying to save the money in the 10% so that we don't end up issuing pro forma, and therefore inexpensive, reasons in each case. We'd like to husband our resources, direct our resources in a way that we can have thorough, usable, educational reasons in the cases where we need them.

I should also point out that it's nothing less than what the courts have. You go to the provincial courts, they don't issue reasons in every case. They issue thoughtful, lengthy reasons when necessary, and in inappropriate cases don't issue at all.

I have to tell you that I've been called to task by our membership since Bill 19 was tabled. They feel that the provision dealing with reasons for decision is lacking a very important element, and that is that the parties can ask for reasons, which is good, but there's no limit. A party could theoretically come a year or two later, where we wouldn't have notes, where it would cost us a fortune, and probably couldn't issue reasons. My members, particularly my regional vice-chairs, have begged of me to suggest that a limit be placed on the time period to request reasons. Probably 30 days is fair.

I have to tell you that we're very gratified that our power to name representatives has been expanded. We've been involved in many cases over the last year where an order would have been appropriate but is not possible because the patient or resident is not capable of expressing agreement, and that's being changed to "expressing opposition."

The current requirement as well that limits the breadth of our orders we've found to be very oppressive of many of the people who come before us. So we're quite ecstatic, on a very personal level, to have that extra bit of power because it hurts us to say no in cases where we could really help people by saying yes. Perhaps that's not a professional position to take, but as individuals we're very grateful for that.

A few other issues of concern to the board. There are provisions in the HCCA for an order allowing the board to order the public guardian and trustee to arrange counsel, but for reasons that seem to defy explanation, these same powers are not extended into the Substitute Decisions Act, where we're now being given the power to review statutory guardianship for property, and they're not extended to the Mental Health Act. So if you're found incapable of consenting to treatment and you're before the board, and it looks like you have legal interests that need defending and you don't have a lawyer, we can do it.

Now, we've only done it three or four times over the year—this is not a big mover or a big money item—but



we're quite terrified that it doesn't appear that we have that power if you are now under the SDA. With the amendments, if the right to control your finances is taken away from you because you're found incapable and you need counsel, we wouldn't seem to have the power to order counsel appointed. We're troubled by it, and we're also troubled by the lack under the Mental Health Act. I'm not a policy person, but I have difficulty in imagining that there's any sort of policy reason for it. I wonder if it's simply an omission.

Also, on the topic of statutory guardianship for property, I'd like to contrast the powers given the board with the powers that a court has in reviewing a guardianship application. To look at the guardianship test that a court is supposed to apply, first it has a specific test and then it basically has what I call an "if it ain't broke don't fix it" provision. If there's no reason to grant the order, then quite properly the Legislature has instructed the court not to grant the order. If there are other mechanisms in place to guard the person's interests, the court isn't supposed to grant the order.

That's a policy the board has followed for many, many years in financial capacity matters. We think that it's exceedingly important not to inflict the powers of the state on someone if not necessary. We're very troubled that we haven't been given the same flexibility as the courts. We could be in a position where somebody is before us, either under the Mental Health Act or under the Substitute Decisions Act, after appealing a statutory guardianship for property where the person probably is incapable, no doubt about it, but there's no problem; there's the family available, everything is going hunky-dory and there's just no fire to put out anywhere. It appears that we might, because of these provisions, be put into a position where we have to put blinders on and make an order that would be exceedingly unjust, and we're very troubled by it. So we'd ask you again to look at that provision. I'm not sure that again it isn't simply something that somebody missed in the drafting. The exact wording that one needs is in the authority of the court when doing a guardianship order.

The last thing that I want to talk about is the issue of education. I should say that the concern that I express on the issue of education I bring not just on my own behalf and on behalf of the board but also on behalf of Dr James Young, the chief coroner of Ontario, who has asked me to convey his concerns in this regard and express his regrets for not being able to be here. He has conveniently arranged to have to be in Nashville, he told me, at some exceedingly important conference for some time, and he said we have to believe him. His office has assisted me in compiling materials that you have and that I'll be handing up.

1610

I have to tell you why the issue of education is so important for me personally. Before I was appointed to the board in the late 1980s, as I mentioned, I was at the ministry legal branch and as part of my job I would go to inquests after the death of psychiatric patients and monitor on behalf of the ministry. Time after time we'd hear the same story: Someone had walked into a hospital or been brought into the hospital, the doctor refused to commit them, refused to sign the form 1 in the belief that

they didn't meet the criteria. The doctor would testify, "We have all these horrible laws in Ontario that say you have to have a nuclear device in one hand and a machete in the other before we can commit anybody, and this guy wasn't going to commit murder and mayhem for at least 20 minutes, so we had to let him go," kind of thing.

Then we'd hear the witness or the police officer who'd scraped the body off the Don Valley Parkway. Under the Bloor viaduct seemed to be the popular place. Then we'd hear the legal expert, one of these people sitting behind us, or Mr Sharpe, who'd be called to the stand and would explain that that isn't what the Mental Health Act says at all, and the jury would recommend education and outreach. As I left I'd hear the family being interviewed by CITY-TV—they really are everywhere—saying, "At least our son didn't die in vain; something's going to be done." And darn it, nothing ever was done.

I attended more of those inquests—in fact, I've compiled them with the assistance of the office of the chief coroner and you have a summary of those. I've brought full copies of 10 inquests since 1989. The Clemens one you're familiar with, but there's lots more where, in every single case, the jury recommends education and outreach and nothing is ever done.

There is no doubt that many health professionals misunderstand or underestimate their legal authority to treat and admit patients. Ignorance and misuse result in increased expense in the health system and unnecessary suffering and have contributed to many of the tragic situations that I've referred to. The Clemens inquest—I think you met the parents this morning—is only the latest in a long series of inquests into deaths that are at least partly attributable to a lack of knowledge of the law.

We receive calls every single day asking for clarification of issues associated with the acts. It's probably not our mandate. I could probably get into trouble for doing it. We answer the calls anyway because I don't want to read the paper the next morning. These calls are frequently from desperate families or friends or confused and frustrated professionals.

I have to tell you, by the way, that there could have been a companion to the Clemens inquest because just about the same time that arose, I got a call—I was out in Vancouver. I never go anywhere without my cell phone now because of these issues. I got a call in Vancouver while I was out there at a conference, just as important as Dr Young's conference, from a doctor who is chief of staff at one of the major hospitals in Toronto who had somebody in a situation not dissimilar to the Clemens case. But somebody had said, "Call Mike Bay at the board."

She honestly believed that she had to let this young woman slip away and I had to grab her by the scruff of the neck through the phone lines, refer her to the emergency provisions in the act, push her to call her lawyer, explain what she had to do, and I basically said, "Go back to the room and stick an intravenous in her." It was a little anorexic young woman, a terrible situation. And that young woman is still with us. Sorry, I get a little choked up when I think about that one.

But the message is that, certainly in the view of the board, the current educational efforts are not sufficient.



Families and consumers are confused and troubled and have no one to turn to for help. Health professionals in institutions are in desperate need of reliable, neutral information.

We believe that two things are required and I think you've heard—at least people have called me and said they were putting it in their submissions. Maybe they were just jollying me along. It's interesting that one of the few things that unify the patient advocate groups and the provider groups is the need for education.

We think that two things are needed, neither of which is very expensive: Make the board—we're pleased to take the responsibility—or make somebody else—I don't care who you give it to—make somebody responsible to do education on an ongoing basis in their area. It has to be somebody's legal responsibility so you can justify budget.

It also has to be somebody's legal responsibility so that next time there's an inquest, Dr Young can subpoena the person who is responsible for educating the doctors in the province and say: "Why wasn't this done? What happened here?" If that has to be me, then that's fine. Again, I think it should be the board, but I'm happy if you give it to anybody.

The second thing—and it's been suggested many times; I didn't make this up—is the creation of a 24-hour access line to legal advice in consent and health law so that that doctor at Sunnybrook will have a number on the wall in the emergency ward to pick up and get legal advice. It wouldn't be expensive; my guess would be \$60,000 to \$80,000 a year. The board could supervise it, although not provide it, because that would be a conflict.

The legal branch of the Ministry of Health could take over the responsibility. It could be farmed out on a fee-for-service basis. For instance, now in Nova Scotia I'm told if you're arrested at 3 in the morning and hauled into the police station and you want to talk to a lawyer, they call an 800 number. It's actually a lawyer in Toronto who answers your call, some private outfit doing it through a law line. Again, I think basically it's \$60,000 a year that costs the Nova Scotia government. All we really need are maybe three young lawyers with some knowledge in this stuff on retainer on an annual basis and a schedule to split it up three ways and give them beepers and cell phones—not an expensive business. But we can't live without it.

I'll pass up in a second the inquest verdicts. I've got summaries of the educational recommendations, which I understand have been distributed. One that I particularly remember is Mavis Jones, who was a psychotic woman who many months before her death told her sister that she was going to take her own life on her birthday—so we knew the date of death months beforehand—and told her sister what she was going to do.

The sister consulted a local physician, who mistakenly didn't think he could do anything; consulted a local justice of the peace, who mistakenly thought that he couldn't do anything; spoke to the local health unit, who mistakenly thought nothing could be done. This woman spent two months trying to save her sister's life. I testified as the expert at the inquest, one of the most horrifying things I've ever participated in, so you can see that I take this one a little personally. I've been giving

this message for about nine years now. I think it's time we do something with the educational issue. I can't put it any more strongly than I have.

My purpose here today was to answer questions, so I'd better shut up and leave some time.

**Mrs Johns:** I'm going to pull a Frances Lankin from Bill 26 and ask all my questions at once so I get them all on the record. That seemed to be the way they worked in the last committee.

What I really need to know from you is, we've heard a number of people talk about the one-person board, and one of the things that I have tried to comment on is the wide breadth that person would have, the experience he brings to the table. A number of people have suggested that this person needs to be able to assess capacity also, so I'd like you to comment on that and how the one-man board works or how the board works and whether that's a necessary qualification.

The second thing I wanted to know was, with these written reports, if someone didn't call in 30 days for their report and they needed to go through another process again, would that documentation be utilized a second time? Have we lost it forever? That I think I need to know; also, to see if we have to have this in writing all the time.

The third thing is, we've heard criticism about the health practitioner or provider being a party in an application to appoint a board-appointed representative. Can you comment on the need for this, and the downsides?

**Mr Bay:** Yes. Let me start with the third one first. I didn't hear all of Peter Singer's representation. I wonder if that was in his. I know it's an issue that's concerned Peter in the past. You may have heard it from other folks as well.

This touches on the first question as well. While we're an expert body, our expertise is not as health care providers, though we have a health care professional with us whose job it is to help us understand the professional evidence and perspective. Our job is in hearing evidence, just like a judge does, and making decisions. In the case of appointing representatives, we can't get to square one unless we have some idea of what the incapacity is and what some of the surrounding information is.

Under the Consent to Treatment Act, the provider is not a party, and what we find is that we have to convene in 95% of those cases and then adjourn and subpoena the provider anyway. What we're doing is wasting everybody's time, holding up treatment and causing a roadblock.

We've asked that the professional be a party as a signal to their necessary attendance at the hearing, to their participation. We need them there to help us do our job. If there was wonderful documentation and wonderful reports—but the world doesn't work that way in these cases. It would cost more money to insist that everybody produce these lengthy reports for the hearing, and they wouldn't look right anyway. That was our recommendation, so I'll take the rap for that one as well, and we recommended it because we've had difficulties without it.

1620

The single-member board: I mentioned that our job is not to do assessment. We don't assess the patient who is



there before us. Patients don't have to come to the hearings, although they do in 95% of the cases. Our job is to hear evidence and make a decision.

The capacity assessors are certified by the office of the public guardian and trustee. Many of those are lawyers. Lawyers have some expertise in that area, although I tend to think less than some other people think, quite frankly. But the people on the board have been doing this for many years. We've asked, and the government has agreed to write in a provision so you and the minister can't find somebody and stick him on my board under this provision who's going to do this. They have to go through two years of training and experience and then qualify to do that. They have to have expertise in adjudicating capacity.

We feel that's all that's needed, again keeping in mind that we don't evaluate the patient. You don't bring the patient before me and I second-guess the doctor; we're hearing evidence and making a legal decision. We certainly feel that the safeguards are there, but that's for the Legislature to decide.

Reasons for decision: There'll be a written decision issued, saying the person is capable, not capable, involuntary, not involuntary; in fact we'll probably expand that to a couple of lines of explanation. Would it be useful a year from now to see those reasons for decision? Sometimes it might be, just like any other documentation in the chart. Yes, I really wish I had the money to produce reasons in every case. I think they're useful to hospitals, I think they're useful to us. The question is whether they're \$275 useful, which is the average cost of producing a set of reasons for the province, and whether we can sustain that or we can better use the money somewhere else.

That's a decision for you folks to make. Yes, I'm kind of sorry about that recommendation. I made it anyway, because I don't think we're at a stage where we can say: "These are all the things we need money for. Write us a cheque." We have to be responsible and decide where the priorities are, and that's one of the things that has to give just a little bit. That's certainly our view.

**Mrs Johns:** Do I have any of my time left?

**The Chair:** That's been five minutes.

**Mrs Johns:** Fifty-five minutes? Thank you very much. From the standpoint of the written report, I understand that everything—

**The Chair:** I'm sorry, Mrs Johns, you misunderstood. I said that was five minutes.

**Mrs Johns:** Oh, I'm sorry. I thought you said I had 55 more minutes and I was so happy to take it.

**Mr Ramsay:** Mr Bay, I would like to thank you very much for your presentation. Just to say to the government, I think it would be helpful for us, certainly for next week, to have government comment on some of the recommendations you've made. I'd be interested in hearing what the government's response is to some of this. That would be interesting in our deliberations next week in clause-by-clause and looking at amendments.

I appreciate very much your—more than suggestion, your pleading with us to make sure that education be pursued with this so that all the people working with this act will be more up to speed and lives will be saved. I

appreciate that and I think that now that the government has embarked upon a new act, that's probably the appropriate time when a new education campaign would have to begin so that people are informed of the changes. It's probably very timely and I would certainly support your suggestion that once this bill is passed, that education program start again so that people know what their obligations are.

**Mrs Boyd:** Thank you very much for coming. My colleague was just saying we wish you had come the first week so that many of the fears that people have expressed during the time we've been having hearings might have been put to rest. I'm glad that you're here now, and it's very helpful.

As you are well aware, the intention obviously with the Advocacy Act was to have the educational function be one of the major functions of the Advocacy Act. From the time it was passed in 1992, that was the vision. It's not that anybody here disagrees with the educational function; it's just who should do it. I understand from what you said that you think your board, given the cancellation of the Advocacy Act, is the obvious place to lodge that.

**Mr Bay:** But not necessarily the only one. My concern isn't that we do it; it's that somebody have the legislative mandate to do it.

**Mrs Boyd:** I gather, since obviously a lot of your recommendations have derived from the fact that you don't have the budget to do this job the way you ought to be able to do it, you would expect a budget that would allow you to do that education appropriately.

**Mr Marchese:** Or somebody.

**Mrs Boyd:** Or somebody. You cannot educate without money.

**Mr Bay:** You can educate without money. I think we have a certain reputation for doing things off the back of an envelope. We need the envelope, but I don't think you need a heck of a lot of money to do things, with respect.

**Mrs Boyd:** With respect to the one-member board, you're very fond of using it, and obviously the government has learned from you to use the situation of a judge. A judge sitting alone deals with criminal matters and incarcerates people, but of course the burden of proof is much higher under the criminal law than it is under this law. You are obviously operating all the time on balance of probability. You could hardly be operating in any other way, whereas a judge who incarcerates or confines somebody is required to base that decision on beyond a reasonable doubt.

So I'm not sure that, for the uninitiated, that analogy is necessarily the best analogy in the world. That doesn't mean to say that under some of the circumstances you've described, some of the fears of some people about a one-member board might be less. You say that you always have a health care professional offering you health care advice, in other words, there's a staff person who offers you that expertise?

**Mr Bay:** No, this isn't legislated in all areas, but traditionally the board panel sits with one psychiatrist, one lawyer and one community member. We don't have any staff people; we have one board member who is a psychiatrist.



**Mrs Boyd:** But if you were one board member, what would you have to have to give you the resources in terms of even interpreting—you know what doctors talk like. How are you going to know? How are you going to interpret what you're hearing?

**Mr Bay:** Let me answer both of those. First of all, when I compare to judges, really what I had in mind wasn't the criminal courts; I had in mind the judges who over the years have done the Mental Incompetency Act cases and the guardianship and exactly the same stuff, review of mental health stuff, that takes place in most jurisdictions. The very issues that have been assigned to us have been around the courts for years and they're generally done by a single judge, who may be a generalist, who may be someone with some expertise who does this. With respect, I think the comparison is valid.

The ability to talk doctor talk, if I can use that expression, an expression I'm fond of: I think my board members—and again, we're not talking about taking Green Hornets and injecting them into this process; we're talking about people who've been doing it. Look at me personally: I've done thousands of these hearings over the last couple of years. I can understand medical evidence. I may need the doctor to slow down and explain something to me.

The one area where I worry just a little bit about the single-member board is that I find that having a doctor with me on the board is of great assistance in those cases where we have a health professional who's trying to pull the wool over our eyes, just like my particular expertise is helping when I have a lawyer who's pulling the wool over our eyes. When we go to our deliberation closed session, it's the professional colleague of the witness who can tell us that the emperor was wearing no clothes.

The single-member board might make the board a little more conservative in its actions. I don't know whether that would even be measurable, but other than that, I think the expertise is there. We have a professional cadre of judges who have doing this for a long time; these are not amateurs.

**Mrs Boyd:** Did I understand you to say that you would like the act amended to require the health-care provider, whoever that is, to be present at your hearings?

**Mr Bay:** It's in the bill. The health-care provider is—

**Mrs Boyd:** Is permitted but isn't required.

**Mr Bay:** As a party to each of the—

**Mrs Boyd:** But you're talking about subpoenaing them. Should it be a required presence?

**Mr Bay:** I don't think we need that. Making them a party is enough of a lever for us; even without them being a party, we've subpoenaed them when necessary, but it's a waste of time and a waste of resources and gotten doctors' backs up. The goal isn't to get adversarial, as we keep hearing, the goal is to make it work.

When we call pre-hearing conferences, which we intend to do in long-term care—our ultimate goal would be to never hold a hearing. We would like to resolve things pre-hearings. I can't force the doctor to be there under the Statutory Powers Procedure Act unless he or she is a party to the matter. So it's a matter of us wanting to make sure that all the players are parties, so that we can resolve things.

1630

**Mrs Boyd:** The lack of written reasons is strictly a budgetary measure. It's not something you would prefer to recommend but it's something that you—

**Mr Bay:** I recommended it.

**Mrs Boyd:** —you feel forced to have recommended because of your budgetary constraints.

**Mr Bay:** I keep reading about government offices being told that you have to cut this and you cut that. Nobody has come to me and said that you have to chop off 5% or 20% or 150% from your budget.

**Mrs Boyd:** When you're increasing your workload by this much.

**Mr Bay:** Well, (a) I'm increasing my workload and (b), as the head of a government agency, I have the obligation to try to work with government policy. I know I'm spending health care dollars and I have an obligation to save anywhere I can.

**Mrs Boyd:** But in view of the real fear that's been expressed, how much does this cost you a year to present written reasons? You say that in 90% of cases, people would want them anyway. So you're only saving 10% of that cost. Do you really think, with the angst that's been expressed to this committee, that is really a worthwhile motive, if that's your only motive.

**Mr Bay:** I'm spending about \$275,000 a year producing written reasons. You have to add to that some secretarial; that's professional time. If we're talking about 10%, that's real money to me, quite frankly. That could fund about 30% to 40% of the educational budget—10% of the reasons.

**The Chair:** Mr Bay, we thank you for your attendance today. It's been most valuable to everyone here.

PAUL MILNE

**The Chair:** Mr Paul Milne of Simpson, Wigle, welcome. You are our last submission for the day.

**Mr Paul Milne:** I know it's late in the day and I don't intend to read my submission. I'd basically like just the opportunity to speak with the members of the committee, and thank you for the opportunity to do that.

I've asked for the opportunity to speak with you today to perhaps have more of an opportunity to bring before you the kinds of planning principles that the act allows so that hopefully, as was mentioned earlier, the concern about the vulnerable may be diminished if we use the legislation positively, in its best sense, to plan for our own vulnerability. That is a wonderful strength of the act. So you're going to hear basically a positive commentary from me.

I had the opportunity after the Fram committee report to be a member of the bar association committee which submitted the briefs on Bill 108 and had the opportunity to submit the second brief. For me, that five years our committee spent together—I believe it was almost five years—taught me a lot about formulation of legislation. It taught me a lot about theories we developed versus what has happened in practice.

Today I'd like to direct my comments to some of the wonderful planning tools of the act and how I think the amendments will enhance those planning tools. As I said,



I have become very strong in my belief that good planning cures a lot of our concerns about vulnerability and certainly not to diminish that.

What has happened since royal assent in 1992 and especially since proclamation, what I have noticed, and I can certainly tell you many other lawyers have commented to me that they have also noticed, is very much a change in the willingness of people to plan. Before the act came in, there was that stumbling block of being able to only minimally plan in so far as incapacity for property was concerned.

As you know, we had an opportunity but not a great opportunity and we had very little opportunity to plan for our incapacity of the person. I think that really psychologically impeded people from taking that extra time to plan from incapacity, through it to death and through administration of their estates, and that's what we're finding now. It is much more of a process.

What has happened, too, that I think has enhanced that process, is that we found it started with the Conservatives, went through the Liberals and was finished by the NDP. To me, that's quite a compliment to this province because it showed to me quite a commitment of all three parties, as all three parties had an influence over the bill, to private planning. The private planning sections, I felt, were enhanced on a spectrum.

So this afternoon what I'd like to talk a bit about are some of the planning tools in the act and how I think the amendments will affect them. I'd also like to state that I think the approach that's being used this time of the usage of the public guardian and trustee office's experience in changing legislation, to me, is very, very important. That office, from the very beginning, became a central focus of communication, not just from the public—and many of you know there were thousands of calls coming into that office week by week, was my information—but there were many, many calls coming from lawyers trying to get help and understand what was before them. It's not just that we have now a government office, but we have an office that has a wide breadth of experience from all spectrums. I think those experiences have been reflected in the changes.

I'd like to comment on just a few of them; I won't go through them all in my paper. The witness attestation requirements—I know you've heard a lot about that. As a planning tool—I can tell you there was a tremendous amount of confusion regarding the requirement that the witness have no reason to believe the grantor was incapable, whether it be property or personal care. Was it an active or passive requirement? The passive requirement school of thought said that if they didn't happen to say something or didn't notice in their actions that they may not be capable of giving a power of attorney, you could go ahead and witness the document. The active school, which was the one I subscribed to, felt that you had to set upon a course as a witness to determine that they were capable of giving that document or not incapable of giving it.

The changes I think are suitable for planning and important for planning because, when you plan from incapacity through death, the witnessing requirements on a will now are analogous to those for a personal care

power of attorney in the proposals and a property power of attorney. I think that is important for widening the group of those who will witness. We had a lot of problems going into nursing homes and hospitals and obtaining witnesses. I think that will be diminished with the changes. As I mentioned, with the widening of those who may witness, we'll have much less problem.

I do have some concern about removing from the list the child of the grantor or those to whom the grantor has intention to treat as a child. I'd like to talk to you a bit about perception. The issue there, to me, is one, first of all, in balancing who may witness and who may not. Is it important, the child witness? I don't think so, now that the proposals expand that group of people who will be willing to witness these documents. I balance that against not the potential abuse but the perception by family members. Family dynamics in the estate planning circumstance play a major, major role, and a perception that a child has encouraged a parent to sign a document and has witnessed that document, often creates greater problems than actually exist. I find I have had to deal on a number of occasions with those kinds of perceptions. So my own personal view is that I don't think it's really necessary now to exclude the child of the grantor from that list.

Court-appointed guardians of property and of the person: The proposed amendment by adding section 2.1, allowing the court to appoint a person who provides health care, residential-social training and support services for compensation to an incapable person—again, I quite support that. Those of us who have had long experience before the courts in committee applications, as an example, I think can categorically tell you that it is a very difficult application to obtain in court if the judge is not satisfied. Our judges have acted, sometimes, I think, to an extreme in ensuring that the individual was dealt with in an appropriate fashion, with proper restrictions in the order.

#### 1640

I think sections 25 and 58, for property and personal care, as I mentioned, allowing the courts to set conditions, balance against what I see growing, namely, people outliving their relatives and our mobile families, leaving no one at home with potentially an incapable parent. Parents who come to me and talk about the fact they'd like to appoint their doctor, for example, or a nurse who's been attending on them, as an attorney and are prohibited from doing so, at least now, for the courts, the courts aren't prohibited from doing so, and I very much support the proposed amendment.

The disclosure of personal information by regulation, the three named individuals or groups, the ability to allow disclosure for specific purpose and then to regulate that disclosure, again, I support. I understand the concern all of you have to wrongful disclosure of that kind of information, but the proliferation in the private planning of the need for that information to make private planning work is why I support it.

Let me give you some examples. In drafting powers of attorney, it is now becoming a custom for grantors to exclude someone who's been appointed if they themselves are incapable of their own personal care or if they themselves are incapable of managing property. The way



that's determined quite often in the appointment is by a letter from a doctor. Remember, that's outside the act. That is a personal appointment and a condition on the appointment. Obtaining those letters from doctors has always been very difficult, and rightfully so. Similarly, obtaining that kind of information for applications to court sometimes is very difficult and we go through a great deal of time, trouble and effort trying to get them for those applications to court. I think the limitations you're putting on it by limiting the use or the purpose and controlling it is a safeguard that doesn't frighten me personally.

The obtaining information about the grantor's property—again, I'm quite supportive of that. I'd like to see that expanded to include RRSPs, insurance policies and so on. I've run into the problem already of attorneys not being able to get that information and policies lapsing because the premiums aren't paid. So again, it's a private planning mechanism that I have no difficulty with.

Similarly, the ability to obtain a will, to me, is very important because it telegraphs to grantors of powers when they're preparing them that if they leave specific items of property in a will, they can protect those items of property in their power of attorney by setting conditions that those items can't be sold. Good planning. So I would like to support those suggested amendments and then add in RRIFs, RRSPs and that kind of thing as part of the property.

An area now which is more of a concern to me, multiple powers of attorney and the conflict of laws section. Clause 12(1)(d) that allows for multiple powers of attorney, if you include the statement that "there shall be multiple continuing powers of attorney"—now, we're only talking property here, as you know—is confusing. It confuses me. I'm not sure what it means. I don't know if that means it's mandatory that there shall be other powers, multiple powers. I don't know if that means there shall be powers in existence before the current one is drawn. I can tell you that I have very few clients I've ever run into that even understand what "multiple powers" means.

One way of dealing with that is, instead of treating "shall" in its mandatory sense—if the intent there was to authorize multiple powers, then perhaps that sentence might be changed to read, as I've indicated in my submission, something to the effect of "a continuing power of attorney is terminated when the grantor executes a new power of attorney, unless the grantor authorizes multiple continuing powers." It's more of an authorization than is "shall." A preference for me is not to do it necessarily that way but to simply allow multiple powers by allowing the revocation power to accept other powers of attorney, so that if bank powers have been signed and if—I'll give you an example: I am using limited powers in succession planning for a family business, where a limited power to vote the shares of the business will be given to those who will manage it in an interim in the event of an unlikely death or an untimely death. How do we keep that from being revoked or from revoking a general power?

Frankly, I think it again comes back to the original themes, and one of those is the personal responsibility of

the planner. Talking about the themes of the Fram committee, whenever I run into trouble understanding the act, I go back to those themes, review them and kind of bring myself back. I would personally favour that it's the responsibility of the grantor of the power to accept those that he or she wishes to remain in force. That also allows us, then, to move out of this jurisdiction, particularly in the United States.

I am quite concerned about section 85. I'd like to describe to you briefly how some of us are dealing with it. We have a lot of snowbird clients. Because they're spending so much time in Florida, they often create a relationship with a law firm there. What we discovered is that they have gone in and planned in Florida in case they have a problem in Florida, and they've come to us and planned in Ontario in case a power of attorney is needed in Ontario. The end result of that kind of planning, to me, is the possibility of great confusion. If we're able to clarify the multiple powers section so that it's more easily understood, it allows us to work with the Florida attorneys to ensure that the Florida powers include the elements necessary to make the Florida power an effective power if it's brought into Ontario.

I'd like to give you an example. With a Florida personal care power—they don't call it that, but it's the same thing—someone is injured, flown home with the personal care power. In order to be valid here, it must meet the formalities; it does. But then the next question is, if it meets the formalities, does it, for example, if it has a revocation power, immediately revoke the Ontario power when it's brought into this jurisdiction? I frankly don't know the answer to that.

Secondly, in our conflict of laws section, whose law prevails? If the Florida power, which I have copies of, has a different definition of incapacity, it's brought into Ontario and becomes valid in Ontario, is it that definition that's used in Ontario or does Ontario prevail? I don't have answers to those questions. I simply ask the committee, in your deliberations, to perhaps give some consideration to that.

Finally, I'd like to talk about something that I think is the most important matter to me, and that's personal care powers and compensation for personal care. When I started my own drafting of this, I had the good fortune and time to work with Dr Molloy, who was Dr Singer's—I understand Dr Singer was here earlier today. In my view, they're the pioneers of health care directives in this province, if not this country. I do have a fundamental disagreement with both of them, which I'd like to raise tonight.

But getting back to Dr Molloy, we did a study of 50 clients in a row, and they answered questionnaires. Something I learned in reviewing their powers and starting to relate them, which normally we don't do in private practice, was that in the main people tended to appoint a male as their property attorney and a female as their personal care attorney. In questioning them, it was the issue of confidence in the individual's end skills.

If you go back to your legislation, you all know there's compensation clearly provided for property, and there isn't compensation presently for personal care. Now, the way most of us have been getting at is, as you know, we



have been directing that compensation be paid to personal care attorneys as one of the conditions in the personal care power, and in the property power then directing the property attorneys to pay the attorneys for personal care. Now, I can tell you that some people are very uncomfortable with that.

I very much support the proposed amendment by regulation to establish payment for personal care attorneys. Again, looking at our sample and my impressions since our in effect anecdotal study, many of the women who are appointed work, probably full-time, many of the women who are appointed have children, and to add on the burden, with no pay, of looking after an infirm parent while at the same time a brother is being paid for doing a much lesser job in a property sense, to me it is not fair and I think tends back into the family dynamic situation to create difficulties that I don't think any of us intend to create.

1650

I would like to go further and suggest to you that you bring in a provision similar to the property power, and that's that the grantor can set the rate of pay higher or lower than the prescribed rate. That's what I suggested in my submission.

I'm not here, I think, to try to simply point out this anomaly that I consider to be in the present legislation, but from a family perspective and from private planning, I think it's really important that legislation be enabling so that then people who are giving powers of attorney can, while they're doing it, look at their own families, appoint those whom they have confidence in and then remunerate them, if that's appropriate, and let them make that choice. I think that's very important and I very much recommend that to you.

Thank you. Those are the end of my remarks.

**Mr Ramsay:** I just want to thank you very much for coming and contributing to the process. I'm sure many of your ideas that you've presented today will see themselves in amendments next week.

**Mr Milne:** Thank you.

**Mrs Boyd:** I didn't quite understand you on page 3 of your submission. I thought I understood that you were saying you did not want witnesses to have to attest, and you agreed with that change in Bill 19, but I thought you also favoured the continuing exclusion of a child of a grantor.

**Mr Milne:** Yes, I do.

**Mrs Boyd:** I think just at the end of what you said, it sounded as though you said the opposite, so I'm delighted to hear that, because I think that's a balance and check that—

**Mr Milne:** I apologize and I do favour it. Yes.

**Mrs Boyd:** Good. Because we agree with you that that is an issue. It's been brought up by many of the people who have come, so I think that whole issue of conflict of interest is one that needs to be addressed. That's why most of the consumers who have come have not liked the idea of a paid caregiver, a compensated caregiver, to be able to hold the power of attorney, and I share their concern, because unfortunately there are enough horror stories of how estates have been depleted by that, and I think that's a bit of a problem.

Can you think of any way in which sort of an overwhelming conflict-of-interest clause might be added to the interpretation clause of the Substitute Decisions Act and the Health Care Consent Act that might in fact resolve some of those issues around conflict of interest?

**Mr Milne:** You know, I've thought a lot about that, and I don't have an answer. The problem with conflict of interest is being determined under definite, and when I think of that and then I relate it back to the planning process and I relate it back to my conception of families, I guess for me it first of all is the responsible decision of people in the planning process.

I also have no concern, for example, in the court appointing someone who is receiving compensation, because I have great confidence in the courts from my time in practice, and our judges.

So to protect the potential conflict issue, I'm concerned that this whole other realm is diminished, and I don't have an answer. I've thought a lot about it and I don't have one.

**Mrs Boyd:** But you really feel that the court would be able to resolve that with the conditions that the court could apply.

**Mr Milne:** Very much. I can tell you, I've had a rougher time on committee applications than any other aspect of my practice. The judges—I think part of it's their heart. I also think it gives them an opportunity to really look out for the vulnerable. So that's why I personally have that confidence. I cannot tell you of a circumstance where I don't think a judge did his or her job, in my 24 years.

**Mr Marchese:** I wanted to comment on your last comment, number 6, compensation of attorneys for personal care. I thought that was a very useful observation. I think it was the first time it's been raised by somebody, but I think you're very right. Usually compensation for property applies to men, and for personal care women are probably designated. There's an unfairness around that, and I think we should look at how—

*Interjection.*

**Mr Marchese:** Sorry, Mr Parker, that's what I thought. I think the issue you raised is useful and I think we should look at how we deal with that by some wording, because I think you're right.

**Mr Parker:** Just a few remarks. First of all, thank you very much for coming here today and for assisting us with a very cogent and well-presented paper. Also, when you get back to the office, say hi to Fritz.

A question that I just wanted to address: You touched on clause 12(1)(d), which is the clause that automatically revokes a power of attorney if a new power of attorney is entered into. You're not the first one to discuss this with us. We've had a few recommendations that this provision be taken out altogether so that unless the donor specifically revokes a prior power of attorney, then it remains in place despite the fact a new power of attorney has been prepared, and a person could accumulate powers of attorney over time. Could you give us your thoughts on that proposal?

**Mr Milne:** I have some difficulty with that proposal because of what I've seen, the proliferation of forms; they're everywhere. About a year ago, even before

proclamation, I started asking clients when they came in to do their planning if they had a power of attorney, and I found that quite often, more often than not, they had them in their pocket or at home. They'd already signed a form, but yet they were feeling uncomfortable. Then I started asking clients where they've signed them, and they don't know. It's all over the place. In specially large estates, when we started delving into it, I have discovered they are everywhere: at their banks, their credit unions, they've got them in their drawers at home.

The problem of the proliferation of the form with planning and then with future planning to me is that we're going to go away from the certainty of good planning. We're going to get into that realm of conflict. Now, that may be good for lawyers in resolving conflict, but I don't think it's what we should be doing or do best.

To come back to your point, no, I would not favour that they all stay in place. I would favour that we have the opportunity that we revoke them unless we accept particular powers, because the curative section also comes into play, that third parties can rely on a power if they have no actual knowledge. That curative section should stay, because we do need to protect those third parties and bring the onus back to the grantors of power to be responsible in their own planning and clean up this morass of powers they've got out there. That's my belief.

**The Chair:** I have one question. If in fact it's perception in children witnessing powers of attorney that concerns you, would it not be a logical extension to not permit them to act as attorneys also, where they are actually in a position of power?

**Mr Milne:** No. That's not my belief. First of all, I think the most important aspect of all of these documents

that people bring forward is their confidence in those whom they appoint. Blood is 90% of the appointments. I guess if people look at that document as a job description for someone, perhaps for 10 or 20 or 30 years, for example, Alzheimer's for five years, 10 years before you die, then that piece of paper becomes a job description and it becomes a support group.

Now, good planning says you never appoint one. So where it's children, quite often I find the appointment is a child, but then you couple other people with that child, either other children or friends, with good planning.

To remove the ability to have your child be your attorney I think would be a mistake of all mistakes, because that's what planning is all about, and those are the people that can discharge the duties and obligations.

I can say, Mr Chairman, that I was sceptical in the last act when I saw the duties and obligations of attorneys. So I made them up into a job description that you would have at work. As part of Dr Molloy's study we did, we asked people who had no knowledge of these things, what were their expectations? To my surprise, most of them came up with the group, just about the whole group of expectations that I felt were too onerous. So I learned right away that they weren't too onerous, if people can come up with them on their own.

Now, the reason they came up with them was because they felt that the people they were appointing, namely, their children, would be able to discharge that kind of obligation. So, no, sir, I really think it's important that we stay with that ability.

**The Chair:** Thank you. We are adjourning till 9 am tomorrow, February 21, 1996.

*The committee adjourned at 1701.*

## ERRATUM

No.	Pages	Witness name should read:
J-5	J-74, J-75	Mrs Marilyn Heinz



## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

**Chair / Président:** Martiniuk, Gerry (Cambridge PC)

**Vice-Chair / Vice-Président:** Johnson, Ron (Brantford PC)

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\*Ramsay, David (Timiskaming L)

Tilson, David (Dufferin-Peel PC)

*\*In attendance / présents*

### **Substitutions present / Membres remplaçants présents:**

Brown, Michael A. (Algoma-Manitoulin L) for Mr Chiarelli

Caplan, Elinor (Oriole L) for Mr Conway

Johns, Helen (Huron PC) for Mr Hudak

Kells, Morley (Etobicoke-Lakeshore PC) for Mr Tilson

Marchese, Rosario (Fort York ND) for Mr Hampton

### **Also taking part / Autres participants et participantes:**

Ministry of the Attorney General

Spinks, Trudy, manager, implementation support and counsel, implementation support unit

**Clerk / Greffière:** Bryce, Donna

**Staff / Personnel:** Swift, Susan; McNaught, Andrew, research officers, Legislative Research Service

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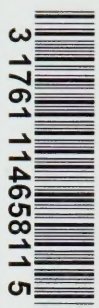












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